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Disability in comedy

# Katie Piper

Facing up to the future

£2.80 Issue 26

December 2009

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### Nominated GP or practice

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Relationship to practice (i.e. patient/carer etc): \_\_\_\_\_

Please give details here about why you think your GP practice's facilities and services are so accessible for disabled people (max 75 words):

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Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Closing date for entries: **8<sup>th</sup> January 2010**

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# editorial

## Home from the war

This year's remembrance season was given greater poignancy by the fact that, not only are service personnel currently on active duty around the world, they are also being killed and injured in combat.

Young people, predominantly young male soldiers, are returning home as different people from the ones they were when they left.

That situation has a number of interesting aspects. How will they adapt physically, mentally emotionally and practically to their new disabled condition? How will they be received and regarded by those of us in the existing disabled community? And most importantly, how will society in general regard and treat them?

To come to that last question first, the true answer will be revealed once the initial rush of admiration, sympathy, perhaps pride, probably pity have passed. When memory of the conflict in which they served has faded.

Perhaps some of those other things will fade too. What they will need is not pity. As many of them acquire pride in themselves for what they now are, they

won't really need the admiration for what they once were or did.

What they will need will be practical support, not just as newly disabled people but of the kind that everyone needs. A job, or alternative means of

**The true answer will be revealed once the initial rush of admiration, sympathy, perhaps pride, probably pity have passed**

keeping themselves and dependants they might have. The means of living independently, so, public facilities they can use, access to the information they require, the ability to vote, the chance, if they want it, to stand for public or political office. In short, they'll need exactly the same things they would have needed had they come home in the same condition in which they went away. The difference is such things won't be available to them by right or default.

And perhaps some of them will choose to join the rest of us in fighting for all of those things for everyone.

# contents

issue 26 December 2009

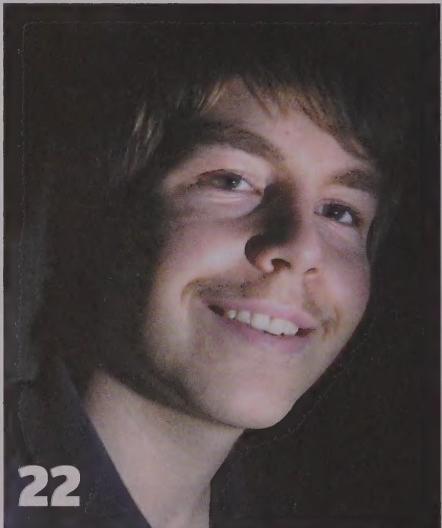


## Katie Piper

Facing up to life in the public gaze

24-28

JAMIE TROUNCE



22

## commentnow

**letters** ..... 34-35

Assisted dying/assisted suicide, charity hits back on scare tactics, why no Blue Badge photo check, more internet banking hassle and getting more disabled people back to work

**Andy Rickell** ..... 36

Active involvement beats cynical consultation

**ask the experts** ..... 38-39

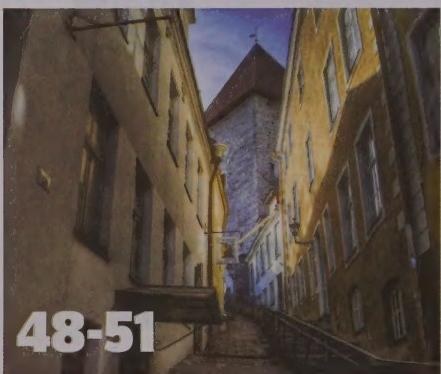
Loss of travel insurance privilege and using websites with voice recognition software

**pete's place** ..... 41

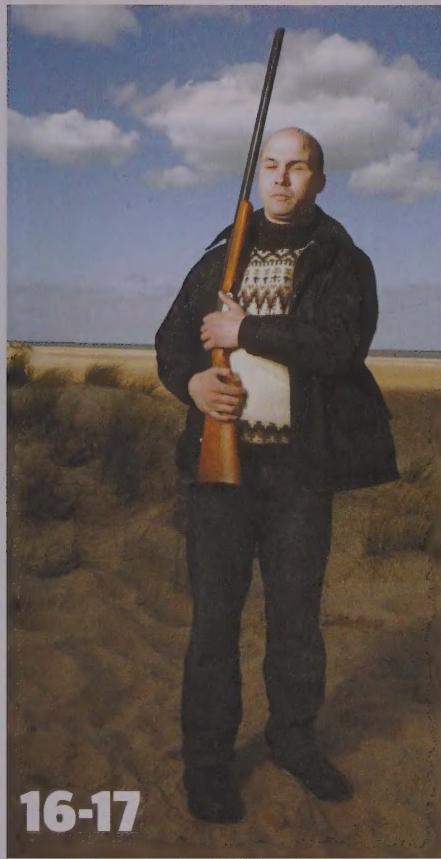
Laughing allowed – when the joke's on us

**guest column** ..... 42

Baby RB, making the right call



48-51



**16-17**



**30-33**

## livingnow

- Katie Piper.....24-28**

Facing up to life in the glare of the public gaze

- Disability and comedy.....30-33**

What are you laughing at? Could it be us?

- up close and personal.....45**

PTSD – the silent witness

- style.....46-47**

Lara Masters talks boots and make-up with Cerrie Burnell

- travel.....48-51**

Talking up Tallinn, Estonia's capital, where old meets new

- tried and tested.....52**

Windows 7 gets an access audit

- road test.....54-55**

Forecourt fury – left sitting it out at the pump

- sport.....56-57**

Reclassified, Derek Malone back in the game

## entertainmentnow

- entertainment.....58-59**

Sounds from the Congo

- webwatch.....60**

Artist Liz Crow shares some of her favourite sites

- backlash.....70**

Paul Carter tries to PIN down his bank

## careersnow

- worklife.....61**

Aiming high – a career in the Civil Service

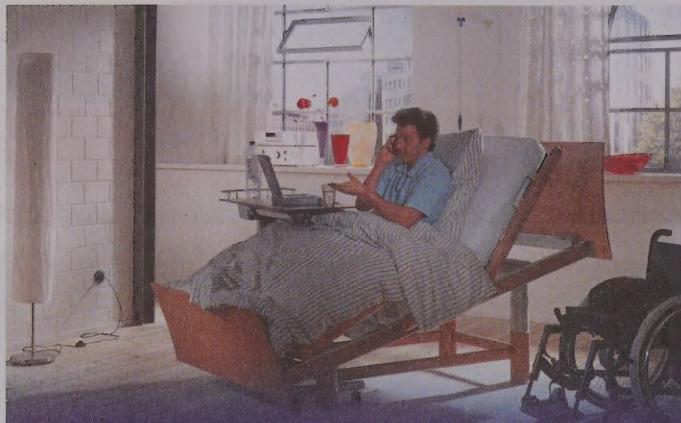
- for sale.....62-64**

- classifieds.....65-67**

- holidays.....68-69**



**46-47**



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# newsview

## Bleak future for attendance allowance

With reforms of social care and welfare reform high on everyone's agenda, Minister for Disabled People Jonathan Shaw suggests to **Sunil Peck** that the Government favours a future without Attendance Allowance

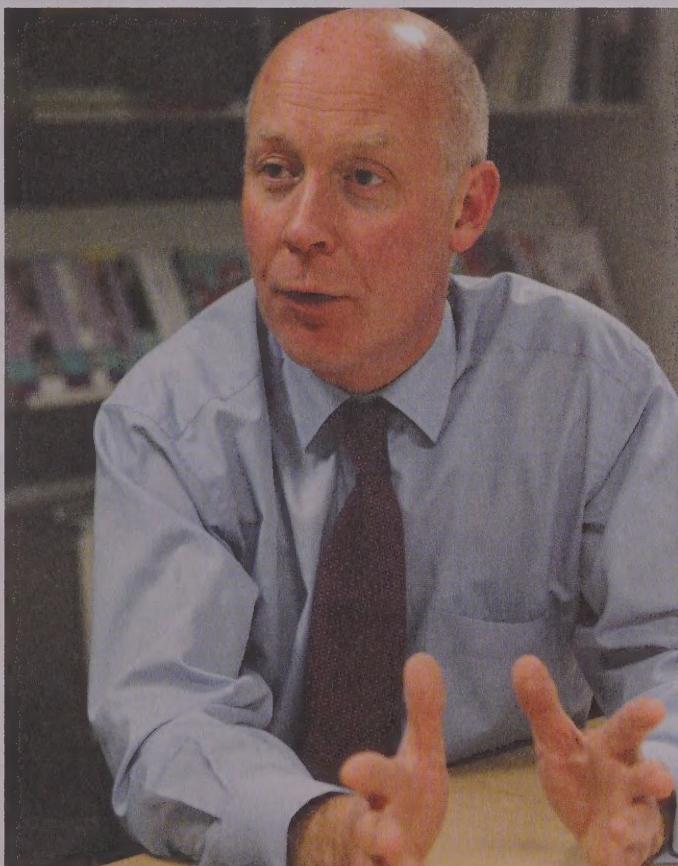
There are signs that, following the recent announcement on Disability Living Allowance (DLA), the Government appears to favour absorbing Attendance Allowance (AA) into general social care funding.

Jonathan Shaw (pictured) insists that older people will not be affected adversely if Attendance Allowance is abolished under a reformed social care system.

"The amount would be put into a social budget of the local authority and people would receive care services in the way that they might use their Attendance Allowance to pay for that now."

So how can he reconcile such a system with the drive for greater personalisation and the right to control, an issue which he says disabled people were particularly enthusiastic about when he met them during a recent tour of disabled people's organisations?

"We've asked people to consider how we will shape future services with the resources we have. If we set in place a national care service where people know what they can expect to have, one of the possibilities of putting in



JAMIE TROWBRIDGE

Attendance Allowance is that it will provide us with more scope in terms of the delivery of social care services."

On fears about the impact of welfare reforms, Jonathan Shaw says he is "content" that more people are being assessed as being fit to work under the tougher regime of Employment and Support Allowance (ESA).

According to Government statistics, of nearly 194,000

claimants for Employment and Support Allowance between October 2008 and February 2009, 36 per cent were deemed fit for work, up from 17 per cent before Incapacity Benefit was abolished.

"We expected there to be fewer people going on to ESA than Incapacity Benefit. It's a year on, we'll have our internal review of the assessment and we're

committed to having an external review each year for the first five years. We're determined to ensure that the assessment process is correct and doing what we want it to do in terms of assessing what people can do rather than what they can't do."

But what about fears expressed by contributors to *Disability Now* that the medical assessments discriminate against people with mental health problems and fluctuating conditions, who are being deemed fit for work and given Jobseeker's Allowance where they receive less money and no specialist support?

"It's not fair to say that the assessment only looks at physical limitations, it does take account of people's social interaction for example."

With the Conservatives promising complete protection for DLA and AA, coupled with ongoing concerns over the Government's approach to those genuinely unable to work, the question which hangs in the air is whether Shaw's future is any brighter than the one he appears to predict for Attendance Allowance.

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# newsupdate

## Disabled students in funding crisis

Cathy Reay

Record numbers of students are being refused or are still awaiting their Disabled Students Allowance (DSA) because of a new system that advisory groups say is discriminating against disabled undergraduates.

DSA applicants have for the first time been trapped by a huge backlog of applications at the Student Loans Company (SLC), with many being turned down or being forced to wait for the essential support that enables them to participate equally in student life.

The SLC is also said to be refusing DSA because of its lack of knowledge of disabled students' needs, after it took over the administration of first year applicants this year.

"The SLC is turning down medical evidence at a much higher rate than local authorities ever did," said Amanda Kent, a disabled DSA needs assessor. "It simply doesn't have the knowledge and understanding of medical evidence needed [to process a claim]."

Lord Addington, who is dyslexic, asked the House of Lords at the beginning of November what action the Government is taking to tackle the problem.



He told *Disability Now*: "What's the point in DSA if it isn't being delivered? Disabled students are now in this environment where their universities just don't know what to do with them because they don't have the facilities they need. It's like asking able-bodied students to write and then taking away their pens. Quiet intervention needs to happen here otherwise it's going to be too late."

Barbara Waters, chief executive of Skill, the national bureau for disabled students, said: "The SLC has admitted it has a backlog of loans applications but what it hasn't addressed is the fact that it doesn't know where half the medical evidence that disabled students have sent in is.

"People are sitting at home thinking their applications are being processed when in reality they are being lost. It's much worse for disabled people because DSA covers expenses necessary for students to participate in lectures. A lot of students can't cope with this head-banging bureaucracy and are thinking of leaving. This is coming close to disability discrimination."

Adam Hyland, the NUS's disabled students' officer, said: "It's disgusting that large numbers of disabled students are still without their DSA. Without this support in place, disabled students cannot access their education and reach their academic potential.

"The SLC has actually

increased the barriers for disabled students by not delivering on time a service that should increase the accessibility of higher education. The situation must be rectified now!"

A Student Loans Company spokeswoman said: "We apologise that some students are still waiting for their DSA applications to be resolved. We understand that this group of students depends on this allowance and we are doing everything we can to ensure that this is processed as quickly as possible."

An independent review of the effectiveness of the Company is currently being undertaken by Professor Hopkin, ex-vice chancellor of South Bank University.

# newsupdate

## Poverty trap deepens, says disability charity

**Sunil Peck**

More than 75 per cent of disabled people with children live below the poverty line, a survey has found.

The Disability Review 2009, published by the charity Leonard Cheshire Disability, surveyed more than 1,200 disabled people in the UK about their experiences of education and employment, social care, citizenship and transport.

42 per cent of those who participated said they were struggling to live on their present income, a rise of nine per cent since 2007 when the first survey was carried out.

The survey also found that more than 60 per cent were in fuel poverty, a figure that compares to 11 per cent of the general population.

John Knight, director of policy and campaigns at Leonard Cheshire Disability, said: "Disabled people are twice as likely to live in poverty as non-disabled people."

"Our survey reveals that disabled people are continuing to have very low levels of income and very low levels of savings, and are clearly struggling to meet even the basic costs of living."

He added: "With disabled people entering the

recession on a profoundly unequal footing to non-disabled people, the need for a government strategy to tackle disability poverty is now more urgent than ever."

Commenting on a finding that 50 per cent of people in poverty are contributing to the cost of their social care, Neil Coyle, director of policy at the Disability Alliance, said: "Councils must assess disability related expenditure, but do not do this well, and leave disabled people unable to afford three meals a day in some cases."

"This is unacceptable and must be addressed by the Government urgently."

Laura Courtney, campaign manager for Every Disabled Child Matters, said she was concerned that 54 per cent of respondents to the survey felt they'd experienced discrimination in the education system.

She said: "Disabled children can have emotional and behavioural issues arising directly from their impairments, are more likely to have mental health problems affecting their behaviour, and can become frustrated and disillusioned with their lack of progress due to unmet special educational needs."



STEPHEN GAMES

Julie Newman (*above*), the acting chair of the UK's Disabled People's Council, said she was particularly worried by the findings because of the continuing threat to Attendance Allowance and Disability Living Allowance for over-65s.

She said: "The prices of clothes in supermarkets are coming down but not all disabled people can access those shops."

The survey also found that more than 50 per cent had no savings, more than 40 per cent believed they'd been turned down for a job because of their impairment and nine per cent had been victims of a disability hate crime.

83 per cent voted in a local or European election in the last three years, a rise of six per cent on last year's survey.

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# Sussex Health Care

Sussex Health Care is an award winning group of care homes that were founded in 1985. Sussex Health Care now operates 16 care homes, predominantly in the West Sussex area, providing nearly 550 beds, incorporating specialist care provision including care for older people.

## Orchard Lodge, Dorking Road, Warnham, West Sussex RH12 3RZ

Orchard Lodge, just outside Horsham, West Sussex, provides care for adults with learning and physical disabilities. This specialist care home with nursing combines the latest technological facilities with a safe and comfortable environment. Activity rooms are available to all service users along with sensory and physiotherapy rooms.

Hydrotherapy services are available in the swimming pool and spa with multi-purpose rooms for structured activities.

## Wisteria Lodge, Horney Common, Nutley, East Sussex TN22 3EA

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For further information or to arrange a visit, please contact Corrine Wallace,  
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# ruthpatrick

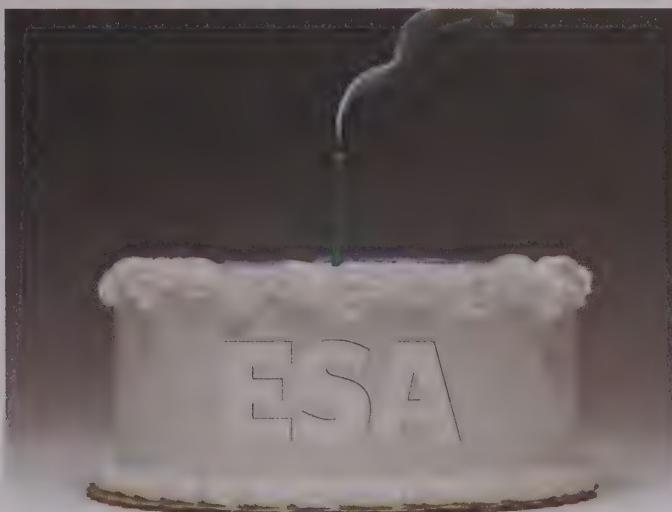
## Time to challenge work test spin

**G**overnment research recently published shows that two-thirds of applicants for Employment Support Allowance (ESA) are not getting through the Work Capability Assessment (WCA), the test which determines whether a claimant will be granted ESA at the higher or lower rate, or refused it altogether. The WCA is spun by the Government as an empowering, enabling test which focuses positively on what an individual can do rather than what they cannot. The test will ensure that individuals get the help and support they need – the rhetoric goes – rather than being abandoned to a life of inactivity on disability benefits. Thus, figures that show that 36 per cent of applicants are being refused ESA, on the basis of being fit to work, are welcomed by the Government as indicating the success of their drive to end the sick-note culture and get us all back-to-work.

Those of us who can see beyond this flawed rhetoric are concerned that the WCA is pushing people with serious impairments onto Jobseeker's Allowance (JSA) with little regard for their



As the Government's new Employment Support Allowance reaches its first birthday, there's no cause for celebration says **Ruth Patrick**



individual circumstances, needs and aspirations. The test is based on an individual deficit model of disability which arbitrarily and abstractly seeks to measure capability against government-set criteria.

Why not look instead at the level of disablement in society and use this as the index against which to measure whether people who class themselves as disabled should be forced into work. Focusing the lens of capability on society rather than on the individual might also encourage positive efforts to address the disabling physical,

attitudinal and societal barriers which remain.

The WCA also runs the risk of creating hierarchies amongst disabled people. According to the mark scored in the test, claimants will be placed in one of three categories. High scorers are entitled to ESA unconditionally whilst those with a few less points will get a lower rate of ESA only if they participate in work-related activity. Those who fail will be promptly placed

on JSA. What is particularly disconcerting is that these divisions are being medicalised and instilled by private contractors undertaking the WCA on the Government's behalf, leaving little scope for claimants to make a positive choice whether or not to identify as a disabled person.

In response, the Government would argue that too many are utilising the disability tag in an attempt to beat the system and claim the more generous disability benefits. This fits the populist rhetoric of benefit cheats but is not supported by the evidence, which shows remarkably low levels of disability benefit fraud.

2010 will herald Government action to roll out WCA as those on Incapacity Benefit are migrated over to ESA. This reality requires strong and concerted efforts by disabled people to tackle Government spin and interrogate the notion of the WCA as a positive development. The time for that effort is now.

### → Have your say

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# politics

## Certainty of uncertain future

As the consultation period on the best way to create a fairer and simpler social care system ends, **Sunil Peck** assesses the impact so far of current proposals on disabled people, some possible future developments and the prevailing mood

The Government's green paper on social care contained elements which were welcomed by disabled people, including a one-off assessment of needs and the aspiration that everybody should have some of their social care needs paid for by the state.

But the positive aspects of the green paper have been overshadowed by the lingering confusion and uncertainty about how the social care system should be funded.

The Government has ruled out funding the new system from direct taxation and has instead proposed three models for funding it, all of which have advantages and disadvantages.

But after promising to make public the calculations underpinning the funding options, they announced ten days before the end of the consultation period that the calculations would not be revealed until early in the new year which is around the time that the white paper is expected.

This makes one wonder whether the Government



REX FEATURES

has doubts about the viability of its own schemes. It has also increased suspicions in some quarters that the consultation period has been nothing more than a PR exercise and that the white paper has been written already.

The issue which has provoked most fears since the publication of the green paper is the future of Disability Living Allowance (DLA) and Attendance Allowance (AA). The Government says that there is a case for integrating some benefits that are not means tested, such as Attendance Allowance, into a central pot to be controlled by local authorities. All that

It took the Government three months, but after conflicting announcements about the future of DLA from ministers and pressure from campaigners, the health secretary Andy Burnham (pictured) ruled out abolishing it for people under the age of 65.

But it is still unclear what will happen to DLA for people over 65 and also which other benefits are under consideration for integration into a funding stream administered by local authorities. All that

the care services minister Phil Hope has said is that anybody over 65 whose benefits are cut will receive an equivalent level of support under the new system and that he is interested to hear which benefits the public think should be abolished.

But for all its trumpeting of the importance of people to engage with the consultation document, it nevertheless went ahead and pledged free home care for people with critical needs six weeks before the consultation closed.

This may look good as an election pledge, but it's still unclear what the definition of critical needs will be and what level of care those people who do qualify will receive.

But it is also unclear whether the current Government will be in a position to introduce this measure or their vision for a national care service after the next election.

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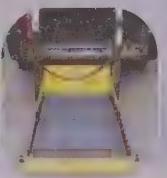


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# media watch



CHANNEL 4  
Of his character, Tim Gebbels says, "He's kind of like me but also not like me. He's quite cynical and also a bit vulnerable. He's got quite a dry sense of humour which sometimes can go a bit far."

The scheduling of the shows has mimicked both soap and reality TV, with two episodes each week. Each one focuses on one of the characters and their back story, interspersed with scenes from life on the island.

"You find out just how fucked up their lives are and why it makes sense for them to go and live on an island," laughs Sophie.

The fact that *Cast Offs* is set as a drama and not an actual reality show mitigates one risk for the channel. Commissioners might have shrunk from creating what could have been criticised or dismissed as the equivalent of a zoo exhibit, but they're saved by the move from reality to surrealism in a drama serial. This change of format allows the disabled characters to be placed beyond the conventional or traditional boundaries either of their impairments or public expectation.

"There've been a lot of disabled people on telly," says Sophie, "and some of it has been a bit cheesy. There are shows like *Beyond Boundaries* and the writers

"Ambitious and darkly comic": Tim Gebbels and Sophie Woolley (both far left) in *Cast Offs*

## Desert Island Risks

With the jury still out on Channel 4's *Cast Offs*, will the high-profile "disability" series be a springboard to stardom for members of its cast or an albatross round their professional necks? **Ian Macrae** talks to two of them

You couldn't make it up. Six disabled people, with a range of impairments, pitched up on a lonely island in the latest experiment in social anthropology masquerading as reality TV. Like the man said, you couldn't make it up. Except someone did.

The documentary series was dreamed up by Jack Thorne and created by him and two other writers, Tony Roche and Alex Bulmer, to

produce a series billed by Channel 4 variously as "ambitious and darkly comic", "satirical, poignant and unashamedly honest" and "brave and ambitious".

Of the six disabled members of the cast, Mat Fraser and Kiruna Stamell are already comparatively well known from appearances in shows including *Every Time You Look At Me* and *All The Small Things* respectively.

Two of the others, Sophie Woolley (Gabriella) and

Tim Gebbels (Tom) are new to television.

"I'm a writer myself, as well as acting", says Sophie. "I write plays and cast myself as all the characters. When I started performing I was hard of hearing and my deafness has progressed. I do signing in *Cast Offs* but my character is like me: her first language is English. So though she signs a little bit on the island, the other disabled characters can't sign so she mainly speaks."

may have found inspiration in that, because you see disabled people being a bit nasty to each other."

For Tim Gebbels, the series also represents an important step in what he refers to as the process of "habituation", by which the more the viewing public sees disabled people on TV, the less strange or remarkable we seem.

"The point about disabled people is that others go around thinking that we're really different. Through shows like this you see disabled people getting

on with each other, getting off with each other, having fights. People with a range of impairments just being people."

### *I'd like to play hearing roles on TV. I'd like casting directors to see beyond my deafness*

One risk for the cast is that many disabled actors like Tim and Sophie find themselves between the rock of no work at all and the

hard place of only ever playing disabled characters. But both Tim and Sophie see a break like this as only positive.

"I'm pretty glad I went deaf," says Sophie, "because I wouldn't otherwise have got this part."

Tim adds: "Many disabled actors get cheersed off that more of us aren't cast in non-disabled roles. I don't get as exercised about that as others. I think [more casting] will come once TV programme makers relax a bit more about disability."

So what hopes does *Cast Offs* offer or leave for the future? Tim and Sophie are clear about what they want. Sophie says: "I'd like to play hearing roles on TV. I'd like casting directors to see beyond my deafness."

For Tim, his ambition takes him to another dimension.

"As a lifelong and quite serious *Dr Who* fan, I'd like to be in *Dr Who*. It could be a blink-and-miss-it part with me being killed in the first ten seconds. Or maybe when Matt Smith has finished, a disabled Doctor? Why not?"

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# disability rights

## Campaign counsels caution on DLA reprieve

As the Government finally clarified its position on the future of Disability Living Allowance, **Steve Donnison** of the Campaign on Benefits and Work cautions against complacent celebration



JAMIE TROUNCE

**M**any younger Disability Living Allowance (DLA) claimants heaved a sigh of relief when health secretary Andy Burnham ruled out any suggestion that DLA for under-65s would be brought into the new National Care Service. They shouldn't have: they

may end up the worst hit by any changes.

The one-and-a-half million older people on Attendance Allowance and the three quarters of a million DLA claimants already aged 65 or over could well be given transitional protection to safeguard their income. It's

a concession that may have to be made to get any legislation through.

But younger DLA claimants, when they reach 65, are much less likely to get a similar deal. Any help they receive will be subject to means tests, constraints on local authority budgets and unappealable decisions about who is entitled to receive care services.

Many will lose out dramatically at 65.

But even that's not the biggest threat. The really big danger is that this is the thin end of the political wedge.

Once you've got people to accept a principle, you can push it as far as you like. It's just a question of patience, whether it's tuition fees, prescription charges or taking benefits from disabled claimants.

First establish the principle that it's OK to take DLA from some people to pay for a National Care Service. Start with an easy target like older claimants. Once the principle has been accepted, just keep driving the wedge deeper.

After all, 65 isn't the retirement age for women and soon won't be for men either. So, if 65 then why not 60? Why not 50? In

fact, why shouldn't everybody contribute to the National Care Service in this way, regardless of age.

Of course, there's every chance that Labour will lose power next year. But it's not a certainty and, whatever happens, Labour seems determined to make the cost of care an election issue.

**• This may be the thin end of the political wedge. Once you've got people to accept a principle, you can push it as far as you like. •**

Other parties will be gauging the strength of opposition to these proposals carefully, as they decide on their own positions.

So, if you want to keep your DLA, now isn't the time to relax. Now's the time to contact your MP, preferably in person and let him or her know exactly how unlikely it is that anyone who wants to take away your financial independence will get your vote.

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## Zambian positive attitudes

I am 36 years old and live in Petauke, Eastern Province Zambia. I am deaf and HIV-positive.

I lost my hearing as a result of a severe case of meningitis during my childhood. Growing up and not being able to communicate was difficult, but I continued to try and live a normal life. I have two children, aged 15 and 12. Their father, my first



While being deaf and HIV-positive can be a frustrating and isolating experience, **Susan Mshoka** believes that's not to say you can't live a positive life

husband, passed away in 1998. It was not long after I remarried that I fell ill. I started to get headaches, lose weight and developed tonsillitis. After an operation on the right side

of my jaw due to my tonsillitis I was encouraged to go for voluntary testing and counselling. It took a lot of persuasion to get my husband to go with me. When we were both told

that we were HIV-positive I was very sad and disturbed. I thought it was the end of me.

To help me come to terms with my condition I drew on the support of counsellors and people living with HIV and AIDS, but it was difficult to find the help that I needed because I was struggling to communicate. There are very few HIV/AIDS

counsellors and healthcare workers that are trained in sign language and I can't afford to hire an interpreter. This made discussing my problem that much harder, and visits to the hospital and clinic became difficult as I had to write everything down. In 2004 my health began to deteriorate rapidly. I was unable to continue working and with two children to support money became a problem. Not knowing who to turn to, it was in my role as chairperson for the deaf women's wing of the Zambia National Association of the Deaf

**I was given the opportunity to take part in a new income generating project. The project involved supplying payphones to local communities where there was no access to telephones and I used the profit I made to support my children**

that I heard about the Zambian Federation of Disability Organisations (ZAFOD).

ZAFOD is a Zambian based civil society organisation that is working



**Members of the Nadezwe Disabled Co-operative which runs the HIV/AIDS awareness programme funded by DfID**

to ensure that disabled people are not excluded from HIV and AIDS services that should be open to all. They enrolled me onto an HIV/AIDS awareness training programme which helped me to accept my status by teaching me about HIV/AIDS and living with a disability. As part of the support received from ZAFOD, I was also given access to antiretroviral therapy which made me healthy enough to return to work, and to help supplement my income. I was given the opportunity to take part in a new income generating project. The project involved me supplying payphones to local communities where there was no access to telephones and I used the profit I made to support my children.

I know that the skills and contacts I have developed

through the support of ZAFOD will stay with me forever. I feel lucky that the training I received has allowed me to pass on my knowledge to help others. I now volunteer at a school for deaf children in Petauke to help raise awareness about HIV/AIDS issues, and my hope for the future is that I am able to become a full-time teacher. When I get the opportunity I also attend workshops in Zambia

**I drew on the support of counsellors and people living with HIV and AIDS, but it was difficult to find the help that I needed because I was struggling to communicate**

and the region to tell my story, so that people realise that being disabled and HIV-positive does not mean you can't live a positive life.

I still worry about how I will be able to support my children, especially now as they are getting older. Unfortunately the payphone business that I was involved in was no longer sustainable but I know that the financial management and business skills that it helped me to develop will be beneficial in the future.

## INFORMATION

The UK Department for International Development (DfID) provided support to ZAFOD through its five-year £20 million HIV/AIDS programme: Strengthening the AIDS Response, Zambia (STARZ). The money was channelled through the Zambia National AIDS Network which provides a grant-making facility to civil organisations working on HIV and AIDS issues. The STARZ programme came to an end in September 2009 and some of its successes have been documented in the short film 'A Shared Future' <http://www.youtube.com/watch?v=OmZddSanMKI> produced by HLSP, who also managed the STARZ programme on behalf of DfID.

# onetowatch

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A "cop apprentice" by day and a science fiction writer by night, 19-year-old Martin Hepworth has seen his first novel published. In *Empire of the Machine*, 12-year-old Charles uses his psychic powers to save the planet from invading alien machines bent on conquering Earth and wiping out humanity. In his day job, Martin uses his filing powers to fight crime from Kendal police station in Cumbria.

### What's the best thing about being disabled?

Asperger's syndrome increases creativity and logic: I'm a bit more imaginative, although it does hamper social interactions.

### What makes you angry?

I hate racism: the idea that any one race is superior. And bullying.

### What have people said to you about your impairment? And have you got any good putdowns?

I'm not being snobbish but I was picked on in school because I was more intelligent, not because of Asperger's. They made me



feel small and insignificant but I knew they were jealous so I said, "Think whatever you want but words can't hurt me."

If you were Prime Minister, what one thing would you do to improve life for disabled people?  
I'd crack down on disability discrimination with fines and imprisonment.

usually impressed that someone my age is doing this and not out hanging around on street corners.

### And what do you not like about it?

Writer's block! When I get writer' block I meditate or have a cup of tea and a serious think.

### Who's your favourite disabled person ever?

Bill Gates. He has Asperger's and started out small.

### Do you have any special or hidden talent?

Swimming. I love swimming but I'm not an expert. And skiing too.

### If you didn't have your impairment, which other one would you like to have for a day?

Narcissistic Personality Disorder.

### How would you sum yourself up in ten words or less?

I'm creative, quiet, and I like to meet people.

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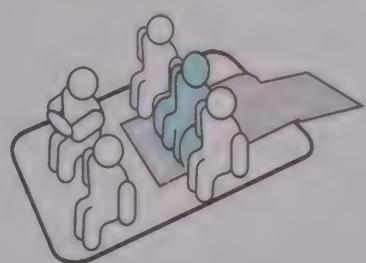


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I'm not going to go on to have cosmetic surgery because I'm not searching for perfection, not searching to restore my old face



# What Katie did next

Recognised first for her beauty, second for her brains, Katie Piper thought she had everything going for her. But when, late last year, her boyfriend raped her and then hired a hitman to pour acid on the model's face, Katie lost the world she knew. She tells **Cathy Reay** how different life is on the other side

**M**y career was based on how I looked; I was defined by it. I pursued that dream because it was something I wanted to do; I wanted to be successful in it," says Katie Piper. And the 26-year-old former model and television presenter was content.

"Everyone I came into contact with judged me on how I looked. If I went to an audition people accepted or rejected me based on my body."

We are sitting in the Chelsea and Westminster Hospital, where, for the past 18 months, Katie has been receiving regular treatment to restore her burned face and neck. Thirty operations later, she's nearing the end, but she has to wear a transparent plastic mask over the lower half of her face until early next year to stretch out her new skin.

"When this happened I told myself I would focus, I'd get through it; I knew I had a lot of surgery ahead of me. Each time I had an operation it was like a means to an end so I could go home and eat an onion bhaji! My family and I started joking around about it; I'd do things like compete with myself on how high I could count before the anaesthetic put me under."

Her jokey attitude is admirable given the turmoil she has endured over the past year and a half. In March 2008 Katie's boyfriend, a martial arts enthusiast who first made contact with



Katie, before the attack

her via Facebook back when she was a wrestling mascot girl, raped and physically abused her in a hotel room in west London. A few days later, he hired a hitman to approach her on the street and throw sulphuric acid in her face.

"[The hitman] had this cup, he looked like he was begging, so I got out some change to give to him and then he threw it in my face. At first I thought it was just hot coffee, but it kept burning. The thing was no-one knew what was going on, it wasn't like I was on fire, people could easily just have assumed I was drunk and upset or something. It took a long time to get an ambulance to get me out of there."

When she did eventually get to a hospital, the burns were so bad that surgeons had to remove the remaining skin from Katie's face and then rebuild it with a skin substitute and graft, much of which was taken from other parts of her body. It was the first time the graft had been completed in a single operation. But recovery has been a gradual process.

"After the operation I was still completely blind and I kept having treatments and my eyes kept being washed. Eventually I could see through my right eye but everything was out of focus, I couldn't read. It was frustrating going from 20:20 vision to blurry silhouettes but then when my vision came back I just thought 'thank the lord'."

Katie went to France to receive aftercare which wasn't available in the UK. She says she has been lucky: "After I had the treatment and psychological help it greatly reduced my disfigurement. When I see pictures of other women with acid burns some haven't been as fortunate as me, they haven't got their features in the right place or been able to speak properly."

The former model still can't see out of her left eye, but she doesn't mind that much. She explains: "I don't want to spend the rest of my time in the hospital. All the things that help me function have restored a good quality



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I've gone from one side of the spectrum to the other; from being what society says is visually attractive and having men chatting you up, all the way down to where, in the early stages, my hair was shaved and I was bright red and people were kind of scared of me.

of life and I'm really pleased about that. I'm not going to go on to have cosmetic surgery because I'm not searching for perfection, not searching to restore my old face."

Katie's two attackers were both given life sentences. As she grew more positive about being able to resume her life, she decided to waive anonymity, so she could help other burns victims. She also agreed to have her experience filmed for a *Cutting Edge* documentary, *Katie: My Beautiful Face*, which aired on Channel 4 in October.



CHANNEL 4

"I want to use my time now helping other people in the early stages of what I used to be in. I've had surgery and aftercare which could easily be available in the UK and [I feel like] it's my duty to share that with people and say to Gordon Brown, this is cost-effective and more importantly, it's more effective with patients. It's something they should be entitled to.

If it works and we know it works then why can't we have it?"

As the documentary showed, Katie spent months indoors during her recovery, too scared to leave the house, scared of what people might think and say about her. She says: "I've gone from one side of the spectrum to the other; from being what society says is visually attractive and having men chatting you up, all the way down to where, in the early stages, my hair was shaved and I was bright red and people were kind of scared of me and reacted very negatively. So it's definitely a shock."

In addition to having to cope with strangers' reactions to her new face, the harsh reality of what she now refers to as a quite superficial profession and social network meant that Katie couldn't resume the job or some of the friendships she had either. "I think that's one of the hardest parts about what happened, it wasn't just losing my appearance and not feeling normal in society, it was losing everything that my world was: my



CHANNEL 4

Katie at home with her family

**I still feel attractive and I don't really see skin that's damaged and lumpy as necessarily ugly. It's different but why does different have to be shunned?**

friends, my job, everything."

But she claims that this has made her stronger as a person. She's had psychotherapy and has also relied on faith to aid her recovery. Now she knows who her friends are. "In my old life, people only helped me because they wanted something out of me or wanted to be with me because they thought I was a good person to be 'seen' with. So when people started helping me after the accident I would



JAMIE TROUNCE

**Katie with her mask on at the Chelsea and Westminster Hospital**

think, 'why do they want to help me or have anything to do with me? Look at me'. It's made me more secure.

"I think my self-esteem was actually lower before because I felt my looks were all I had going for me, everyone judged me on them. I still feel

attractive and I don't really see skin that's damaged and lumpy as necessarily ugly. It's different but why does different have to be shunned? I think sometimes when it's a taboo subject and people are embarrassed or ignorant it's not because people are unkind it's because they are frightened and uneducated."

Although the *Cutting Edge* documentary was filmed just a couple of months ago, given how afraid she was to face the real world, to deal with what she could see in the mirror, it's clear that Katie's attitude to life has drastically changed. And in perhaps the most self-assured statement she's made since we began talking, she says: "Now it is 18 months on and it doesn't bother me, I'm happy in my skin and I'm not looking to please anyone else." ■

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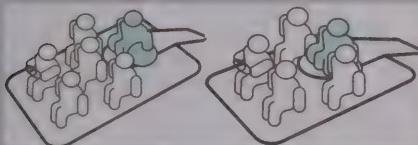
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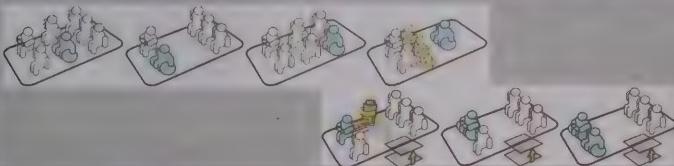
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**H**ow sharp is your funny bone? Let's start with a little test.

Actor and comedian Mat Fraser was once asked by one of those annoying people who feel it's their right to ask such things whether he'd always been "like that".

He looked them dead in the eye and said: "Actually, no. I woke up this morning. Fuckin' arms had dropped off!"

Did that make you laugh?

In the past few weeks, Jimmy Carr and "that joke" have once again brought the subject of disability humour kicking and screaming into the spotlight.

But let's face it, the comedy stage is littered with the corpses of victims and stereotypes. Seaside landladies, Pakistani bus conductors, Scotsmen (mean and/or drunk), mothers-in-law (fat and overbearing), West Indians (relentlessly cheery), gay men (lispingly effeminate), spinsters (butch battle axes), the Welsh (stupid), the Irish (even stupider).

The difference between all of the above and disabled people is that, for the most part, they've fallen off the comedy radar – at least in terms of what's regarded as acceptable – while we appear still to be fair game.

Earlier this year, for instance, when Professor Stephen Hawking was ill in hospital, the Metro carried a cartoon on its front page suggesting that someone should just switch him off and back on again. Those disabled people who dared to express the view that this was less than funny were told simply to see the joke and "get a life!"

Prime Minister Gordon Brown is often singled out for the sort of abuse

# You're having a laugh!



Laugh and the world laughs with you, they say. But if you're disabled, it's more likely to be laughing at you. So, what's so funny about us? And who's allowed to make or laugh at jokes? And, asks **Ian Macrae**, is there such a thing as disability comedy

## That argument would work if there was a level playing field. When disabled comics get as much exposure and media attention, then you can have the free-for-all, because people will be in a position to respond and give as good as they take

which hardly qualifies as comedy at all for the pure and simple fact that he has a prosthetic eye. Imagine the justifiable outcry if someone (other maybe than an African American satirist) was similarly derogatory of President Obama on the grounds of his ethnicity.

But here we have to nail a central question. Is there any value, either in social or comic terms, in drawing those sorts of parallels between disability and other areas of what is often termed the social agenda? Disabled comedian and activist Laurence Clark believes it's important to do so.

It's incredibly useful because disability isn't seen in the same way by a lot of comedians. It's either seen as very risqué, close to the bone, an area for very dark humour. Or there's still not an acknowledgement that disabled people form a substantial part of the audience.

Citing an earlier incident involving Jimmy Carr, where a disabled person left one of his gigs having been offended by a joke which referred to "vegetables", Clark again stresses his point.

"This sort of thing will go on happening until comedians see us as part of the audience."

Adam Hills (*pictured opposite*) is another disabled comedian who's met

and dealt with reactions from disabled members of his audience head on.

"I've had people heckle me on stage for things I've said about disability. They've told me 'You know what, just because you've got one you can't be offensive', and I've had to take that home and think about it."

For Hills, it seems to be about establishing your right to discuss and joke about such things but also be clear about that right and about why you feel able to go certain places.

"I've got a whole routine about sign language and how sign language can be vaguely racist – as a premise which I then take apart.

"This guy in the front at the Comedy Store kicked off and said 'my sister's deaf'. I said, 'ok, but I'm not talking about being deaf I'm talking about sign language'. Basically he threatened to come on stage and punch me. He told me to back off and I said I wasn't going to back off, 'but you listen to the rest of my act and tell me whether you're offended'.

"What he'd missed was the fact that I'd said I worked a lot with sign interpreters so that deaf people can come to my gigs. So it came from a place of understanding."

There's a world of difference between comics like Adam Hills, Laurence Clark, maybe even Jimmy Carr, and others like Jim Davidson or Bernard Manning.

Davidson infamously once refused to take the stage because a row of wheelchair-users had been placed between him and the first row of the general audience. But he's also caused offence, apparently reckless of consequences to his reputation by, among other things, his use of language. He once described rival stand-up Ben Elton as "about as funny



**Mat Fraser**

as woodworm in a cripple's crutch", a statement which seemed calculated to have maximum impact on all sorts of levels.

"Jim Davidson is interesting", says Damon Rose who commissions and produces comedy for the BBC's disability website *Ouch!*

"It's not about his material, it's about him having a problem with disability".

Both Rose and Adam Hills (who writes for *Ouch!*), on the other hand, defend Jimmy Carr's latest foray into disability related material. They point out in his defence that he has both visited and raised funds for service personnel wounded in Afghanistan.

The other defence often put up for

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**Laurence Clark**

him and comedians like him is that being offensive is just part of their shtick. But this is a line which cuts no ice with Laurence Clark.

"That argument would work if there was a level playing field. When disabled comics get as much exposure and media attention, then you can have the free-for-all, because people will be in a position to respond and give as good as they take. But we don't have that at all."

It's becoming clear that humour is both diverse and individual at the same time. So in what is clearly a minefield, comedians and commissioners alike have a difficult path to find. So how does someone

like Damon Rose, a disabled person commissioning and publishing comedy, decide what's funny?

### **Someone once said to me, 'if it's funny it won't be offensive and if it's offensive it won't be funny'**

"It's what feels right", he says. "As someone with my experiences and as a disabled person I have this feeling as to whether something's right or not."

Meanwhile comedian Adam Hills has a mantra to guide him.

"Someone once said to me, 'if it's

funny it won't be offensive and if it's offensive it won't be funny'."

One thing all three of them agree on is what's not funny.

There's an old visual gag which involves the teller sitting down and extending the right arm out parallel with the right thigh, then moving the two limbs in sync, maintaining the distance between them. The question is asked, what's this? The answer, a spastic playing with a magnet.

"It's not funny because it's objectifying and it's very much an outsider telling a joke about a group of people and very much objectifying that group", says Laurence Clark. On the other side of the coin, Damon Rose says: "Humour's funny if it's based on experience and knowledge."

He goes on: "And disabled people have our own humour. I was talking to a short person. She was sitting on a barstool and someone asked her how she got to be the way she was. She said it was through smoking. A few years ago she'd been six feet tall. The person took her seriously and said, 'Oh my god, I'd better tell my wife. She smokes'."

As to why there's all this soul searching, with people scratching their heads about whether or not to laugh, Rose says it's down to lack of visibility of and familiarity with disabled people.

"The confusion happens because the disabled experience isn't in media enough, isn't in drama enough, so it isn't in comedy enough."

And as for what works and what doesn't, again Adam Hills thinks it's really quite similar.

"Maybe the word is empathy. You've got to have empathy with the person. You can't just make jokes about them. You've got to see it from their point of view." ■

# your views

## Assisted dying is not assisted suicide

Recent editions of *Disability Now* have carried negative articles on the "right to die" debate and I think it's important to use this opportunity to clarify the difference between assisted dying and assisted suicide.

I support assisted dying. There's no doubt in my mind that terminally ill adults, making the decision

of their own free will, should not be denied the right to take control over their final moments of life by opting for an assisted death.

I don't however support assisted suicide. Assisted suicide is morally and ethically a very different issue. When a terminally ill adult is nearing the very end of their life and suffer-

ing unbearably, their decision to choose an assisted death is understandable and rational.

But when an otherwise healthy person chooses to end a potentially long life because of impairment or disability, this is a tragedy and they should be given all the support and assistance they need to choose life over death.

To conflate assisted dying and assisted suicide in this debate misrepresents the issue. Perhaps opponents of assisted dying aren't confident enough to argue the point accurately. I hope you will continue to convey the spectrum of opinions on this issue and use accurate terminology in this important discussion.

**Stephen Duckworth,  
Birmingham**

### Charity takes a stand on its mission

I read with interest the views on RNID's presence at this year's party conferences expressed by your contributors Sunil Peck ("Scope bucks charities' negative trend", website) and Peter White ("Putting on the frighteners", *Disability Now*, November) but didn't recognise the way our work was represented in either piece.

Peter White labelled our work as "...the 'give us some money, or this will happen to you' approach". Sunil Peck said that we and other charities had "squandered the opportunity to promote a positive image of disability".

Our stand at all three conferences offered delegates the chance to take our telephone Hearing Check, which is designed to offer

people an easily accessible way to check their hearing.

The stand also showed a film featuring one of our members, Stanley Freed, discussing how living with a hearing loss became easier once he'd acknowledged the problem and got fitted with hearing aids, allowing him to continue to enjoy his passion for music. Without his hearing aids, Stanley couldn't continue lecturing in music at the University of the Third Age. Stanley also spoke passionately about his experience at our Liberal Democrat fringe meeting.

Four million people in the UK could benefit from a hearing aid but don't use one, and on average it takes 15 years for people to take action on their hearing loss.

Anyone with hearing loss can make very positive contributions to society and there are many support



**Shadow Secretary Andrew Lansley MP takes a Hearing Check**

mechanisms to help them do this, such as the Access to Work scheme and rapid improvements in hearing aid technology, but these can't

be utilised if a hearing loss is not acknowledged and diagnosed.

**Jackie Ballard  
Chief Executive, RNID**

## Internet bank problems? 'Go to your local branch'

I was happy with Barclays Bank's internet banking service (see "Banking on access to your money", *(Disability Now, October)*) until it introduced the PINsentry system. I have cerebral palsy with major dexterity issues and I use a communication aid.

Internet banking was ideal for me as I could operate my account independently. I make a lot of payments as I employ personal assistants and employ young students who change frequently. (I'm a young student myself.)

When Barclays first introduced PINsentry, I got them to let me open my page and make payments to existing payees without using PINsentry. They were adamant, however, that I couldn't add new payees without PINsentry. When I explained this was physically impossible for me, they suggested I add new payees either by telephone banking or going to my local branch.

As a communication aid user, telephone banking was a disaster. Everytime I called them, they hung up on me. Going to my local branch rather defeats the object of internet banking and, anyway, I'm now at university 200 miles away

from my local branch.

All the time, Barclays has been really difficult to deal with. They take ages to reply to complaints and I keep getting told to use telephone banking, even though I've explained my communication impairment to them over and over again.

They refuse to make any adjustment (reasonable or otherwise) to make their service accessible to me as a disabled person. That's why I've referred them to the Financial Ombudsman.

**Name supplied, by email**

## Disabled? Then you must be employable

Your article on party conferences ("Party! Party!! Party!!!", *Disability Now, November*) was interesting. I find myself in surprising agreement with the Tories (now there's a first) since, if disabled people are ever to reach the same employment levels as non-disabled colleagues, something needs to change.

David Freud, who worked for James Purnell, has put forward some interesting proposals, which some of us may find hard to agree with, but at least he's coming at it from a "presumption of employability", a phrase I know is used too often but is useful in getting non-disabled people to think

differently about disabled people's rights to work.

Both my kids have a similar condition to me and I'd dread to think that, after all our campaigns, arguments and profile raising, they were offered a job in a sheltered workshop!

Inclusion is tough but while workshops exist, employers and local

authorities have the ready-made excuse that someone else will "look after" or "take care of" "the disabled". No thanks: I'd put the workshops down as another barrier to remove, and accept that the current employees need support (and time) to move into work.

**Graham Hughes, by email**

## Park and chide

Why, when we have to pay to have our photos on our Blue Badges, are they so rarely inspected? I reckon this is the cause of a great deal of misuse: someone puts a Blue Badge in the windscreens and that seems to be enough.

My husband has a Blue Badge and his photo has been checked only once. Just because there's a Blue Badge in the vehicle does not mean it's being used correctly. Why have a photo if it isn't checked?

**Margaret Ackroyd, by email**

I'm a disabled wheelchair user and car driver and I'd like to agree with Malcolm Hosie ("Letters", *Disability*

*Now, October*). I also think people who use disabled parking spaces while sitting in their cars waiting for someone else are selfish.

I recently had to go for a check up at my local hospital and actually approached a man sitting in his car and asked if he could move so that I could use the space. All he did was wave the Blue Badge in my face and say he was entitled to be there.

I think able-bodied drivers should only be able to park in these spaces while picking up or setting down their disabled passenger(s).

**Peter Reed Wilson, by email**

### → Have your say

- write to us **Disability Now, 6 Market Road, London N7 9PW**
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)



## Going beyond consultation

In setting up a scrutiny group on its progress on independent living policies, the Government, says **Andy Rickell**, is putting proper value on the views of disabled people

I was invited earlier this year to become a member of the Independent Living Scrutiny Group whose role it is to report on the Government's progress on implementing its own Independent Living Strategy, agreed last year.

The first annual report of the Scrutiny Group is due to be published around 3 December. I cannot tell you what it says but please go to the Office for Disability Issues' website [www.odis.gov.uk](http://www.odis.gov.uk) where it will be available after that date.

What I do want to comment on is the landmark achieved in the work of this Scrutiny Group, and your opportunity to feed in to its work in future.

Firstly, the Scrutiny Group was set up by government, but is independent. That is unusual.

Secondly, chaired by Baroness Jane Campbell, it is made up of disabled activists and a representative of parents of disabled children who all understand independent living well. Several of us were selected because we

are members of Equality 2025, the Government appointed group of disabled people which advises Westminster government on national policy and its implications for disabled people's equality. Hence it is led by disabled people.

### **The Government deserves real credit for this step forward in the involvement of disabled people as the legitimate evaluators of what happens to us**

Thirdly, it is in my opinion the first time that I can think of when disabled people have been allowed to formally judge the effectiveness of the delivery of government policy. Normally government is evaluated by itself, or via regulatory bodies. Disabled people are often involved in consultation, and increasingly involved in the design of government policy, like via Equality 2025, but they don't tend to give us the chance to tell

them the reality of what government delivers on the ground! That is very "courageous", in the words of Sir Humphrey Appleby in '*Yes, Minister*'. So the Government deserves real credit for this step forward in the involvement of disabled people as the legitimate evaluators of what happens to us.

In a sense, the Government has correctly grasped what disabled activists have been saying, that the weakest link in state support has been the lack of our "choice and control" over that support. So the Scrutiny Group is an additional way of government embodying the means for disabled people collectively to express whether we really are achieving the quality of life that we want, not what others think we should have.

A key feature of future reports needs to be the

informed input of many disabled people on progress towards independent living. The Independent Living Strategy proposed that there should be a "Network of Networks", meaning disabled individuals would be able to pass on their experiences to organisations who would feed it in to the Scrutiny Group. Equality 2025 has been advising the Government on what that should look like.

As a disability activist who has worked at local and national level in disabled people's organisations (DPOs), I know how good DPOs are, and particularly centres for independent living (CILs), at understanding the reality for local disabled individuals. So I hope those networks tap into that intelligence and expertise. Watch for announcements as to how you can feed in your views – contact your local CIL.

### → Have your say

- write to us **Disability Now**, 6 Market Road, London N7 9PW
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Works with Mobilise and specialises in car matters

# Why can't I get the same insurance cover as before?

**Q**I wonder if you could get one of the experts to look at a problem I'm having with my bank. I have a Privilege account, for which I pay a monthly fee. One of the privileges I get for this is travel insurance to cover me for worldwide travel.

About a year ago my bank, the Co-operative, decided to change insurers from Aviva (previously Norwich Union) to Axa. With Aviva my pre-existing medical condition was totally covered, even for travel to the North American mainland.

When I rang Axa to be put through to their screening advisers, I was immediately turned down because I'd had a coronary bypass in 1992.

After much arguing with Axa and the bank, I was able to get cover on the same terms as Aviva, but only for one year.

The question I want to ask is: was the bank in breach of the Disability Discrimination Act by not ensuring that its disabled customers got the same treatment as they did with Aviva?

From what I can gather

from talking to bank staff on the phone, it's not only me but possibly hundreds of disabled customers that this has affected.

The issue isn't one of age, because the terms apply till you're 80. It's wholly a case of discriminating against disabled customers.

Another thing I was advised was that this move was made on a purely financial basis. In other words, Axa was cheaper than Aviva.

Denis Shaw, Whitby



#### Andy Wright replies:

As this question is concerned with insurance I have to be very careful how I answer, given the situation with new Financial Service Authority (FSA) rules and regulations etc.

What I can say is that while I sympathise with you and can see how you might feel that you've been unfairly penalised, this is not an example of a disability discrimination situation.

Insurance companies are quite within their rights to load premiums for what

### THE PEOPLE WITH THE ANSWERS

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they perceive to be high risk individuals, as dictated by their underwriters, and therefore do so, more often than not. High risk to an insurer will be anybody who suffers from heart- or breathing-related conditions, as well as cancer.

I'd suggest that you were very lucky with your previous insurer, but that's certainly not the norm, and the new insurer is acting as I'd expect most insurance companies would do in a similar situation.

# Can voice recognition software navigate complex website forms?

**Q** As a user of voice recognition software, I was very pleased to learn that it's now possible to contact Disability Now via your website and comment on your web content.

However, I found that the form for doing this is very difficult to use with my access software. Is there voice recognition software available that can be used for form filling?

**Léonie Watson (who isn't responsible for our web design) replies:** The contact form on the Disability Now website is reasonably well built and mostly follows accessibility best practice.

Most popular speech recognition programmes include the ability to use web forms. Dragon Naturally Speaking has it as a key feature and so does the speech recognition application that comes with Windows Vista/Windows 7.

The trouble is that most web forms are badly built.

It's frustrating to be able to navigate round a whole website but then not be able to make contact using the form. This means the internet isn't fully accessible to me and someone has to sit with me.

Have other people run into this trouble? I would have thought that a disability magazine would have taken steps to ensure that it was accessible.

**Margaret Ferry, by phone**

Creating an accessible web form is not difficult but the right techniques are rarely taught to budding web designers. Even when web forms are built well, speech recognition programmes can struggle with them. Forms are often complex, and contain large numbers of fields that a speech recognition programme can find difficult to negotiate.

What can be done to help? Here are some suggestions:

**1** Use up to date speech recognition software. As speech recognition technology improves, the easier it becomes to

**Liz Jackson: going great guns**  
She's recently been one of Channel 4's *Millionaires*, she's ambitious, successful and *affectionate* as a mother. And, like lots of us, she's as comfortable in the kitchen as she is with friends and her family.

**Latest News**

**Swiss could call time on assisted suicide**  
The Swiss government has proposed legislation that would make it illegal for disabled people from the UK to go to clinics there to commit suicide

interact with things like web forms.

**2** Train your speech recognition software properly. The more accurately the speech recognition application understands your voice, the easier it will be to use.

**3** Contact website owners. Let people know when you find it difficult to use their web form and point them to best practice guidance for

creating them.

The various software manufacturers are:

- Dragon Naturally Speaking: [www.nuance.com/naturallyspeaking](http://www.nuance.com/naturallyspeaking)
- Windows Speech Recognition: [www.microsoft.com/windows/windowsvista/features/speech-recognition.aspx](http://www.microsoft.com/windows/windowsvista/features/speech-recognition.aspx)
- Accessify (better accessible forms): [www.accessify.com/features/tutorials/accessible-forms](http://www.accessify.com/features/tutorials/accessible-forms)

## → If you have a question for our panel

- phone us 020 7619 7323
- write to us Disability Now, 6 Market Road, London N7 9PW
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)

# **'Alone we can do so little; together we can do so much'**

Disability LIB has a new website. Built using a social networking model, the site is for Disabled People's Organisations (DPOs). Our aim is to build an online community of and for DPOs.

The site includes news and information about a range of issues such as funding opportunities, training, events, campaigns and the capacity building support available from Disability LIB.

We have an online map of DPOs and blogging too. This is for you to show others where you are and what you do. Share with the community DPO news, views, information about events, campaigns, activities or anything else your DPO is involved in.

So please register and take part. Check out the help section to see how you can get started. Contact us on [contact@disabilitylib.org.uk](mailto:contact@disabilitylib.org.uk) or 0844 800 4311 (local rate call) for further information.



Helen Keller 1880 – 1968

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# pete's place

## The one about the comic and the soldier



In the light of that joke by Jimmy Carr, **Peter White** reflects on whether gags about disability are a way of ramping up the shock factor or a release for tension and discomfort

I suppose I'd known Mike for about fifteen seconds when he asked me if I'd heard the one about the blind man who bled to death trying to read his cheese grater. I was a bit taken aback: not by the joke (I had heard it, many times), but by the speed with which it had been delivered! It usually took people about a minute: we hadn't even been introduced.

I wasn't offended: it was 1968, pre-disability consciousness; and I was fresh out of special school, still guilty of telling such jokes myself in order to curry favour, or "put people at ease" as I would probably have put it at the time, with "normal" people. But I was quite interested, even then, in why people felt the need to do it; and I concluded, as I still do, that it was mainly not a sign of hostility or potential hatred, but of their unease and discomfort in a situation they weren't used to.

I'm not sure they are particularly offensive, and

it's much more the "why" than the "what", that interests me. In other words, why is disability on Jimmy Carr's list of things to make jokes about: along with women, and gays? And as Jimmy helpfully tells us, the fact that he was a virgin until he was twenty-six, the theory that these are all things he's uncomfortable with seems to me to stand up pretty well.

In my experience, most of the offence caused by jokes about disability comes from non-disabled people: I reckon that there is an equally interesting debate to be had about whether one has the right to be offended, as there is about whether the other has the right to tell such jokes.

My real contention is that these jokes are better out than in. This stuff is out

there, and needs to be confronted, and debated, and countered.

I understand the argument that giving exposure to such views on the air or in public performances may seem to be giving them tacit approval; I don't agree! You can't fight what you can't see and, uncontested, this stuff just festers. In the case of Carr and my acquaintance Mike, a yawn and a shrug would be much better than a display of outrage: the latter only encourages them!

### ed cetera

What about the bloke with two arms, couldn't decide which hand to wank with!



# guest column

## Baby RB - love, life, death and rights



Disabled mother of a disabled child, **Emma Bowler** considers what the Baby RB case tells us about the judgements that continue to be made about the value of disabled lives



MEHMET CAN

**T**ragic", "unbearable", "intolerable suffering" – these are all terms used to describe Baby RB, the baby at the centre of the recent 'right to life' court case, where an NHS trust and the baby's mother were pitched against the baby's father who wants the child to be given the chance to live.

Baby RB had congenital myasthenic syndrome [CMS], a rare genetic condition that severely limits movement and the ability to breathe. He was dependent on a ventilator in order to survive.

This was the first time a British court has ruled against the wishes of a

parent whose child does not have brain damage.

In most arguments of this nature lack of cognitive ability is used to deem a life as pointless. Ironically in this case the doctors seeking a "dignified death" for Baby RB

### Doctors are not gods, nor are they psychic

had argued that because his brain is unaffected this would have meant his life would have been "unbearable", especially as he grew older and was "catching glimpses of what others can do". What a staggering value judgement about the lives of disabled

people and the way we potentially deal with our situations.

It's actually not that hard to find people who would be rated as very severely disabled who have a much richer quality of life than the average non-disabled person. It's also not that hard to find disabled people, who were written off at birth by doctors, who went on to "defy" medical predictions either in life expectancy or quality of

life. Doctors are not gods, nor are they psychic.

The father's lawyers argued that a tracheostomy, where a hole is made in the neck to allow air to reach the lungs, would have enabled the child to be cared for at home. Hospital clinicians in court argued against such treatment because of his "miserable, sad and pitiful existence".

Although Baby RB was difficult to assess because of his limited movement and expression, he was said to have interacted with and responded to his parents, played with toys and enjoyed music. One doctor said Baby RB could have potentially communicated and operated a wheelchair in years to come.

Unfortunately, when it comes to disability many people, including clinicians – whose opinion is given considerable weight in such cases – think it would be kinder to give us a "dignified, peaceful death" rather than consider that we might actually be capable of having happy, fulfilled lives whatever the level of disability.

### → Have your say

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# upclose & personal

Recent estimates put the number of ex-servicemen in prison at around 8,500. One of them, Jimmy Johnson, talks candidly about Post Traumatic Stress Disorder, the hidden factor that helped put him there



## PTSD - A soldier's tale

I served in a Royal Regiment for ten years and was involved in two conflicts: Aden in 1965 and Northern Ireland in 1972. I was discharged from the army with an exemplary record and was highly decorated for my services in Northern Ireland. I even got a mention in Dispatches!

But in 1974 I was charged with murder, to which I pleaded guilty, and was sentenced to life imprisonment. I served a total of nine years and on release, about 18 months later, I killed another man. I pleaded guilty and was again given a life sentence, of which I have so far served 24 years.

It was only while serving my life sentence that I discovered I was unknowingly suffering from

**The authorities seem to have a very convenient ignorance-is-bliss policy towards combat-related PTSD in the prison system**

combat-related Post Traumatic Stress Disorder (PTSD) because of my action in Northern Ireland, which I had no idea about at the time of my trial.

PTSD isn't used as a

mitigating circumstance in trials, mainly because people standing trial aren't tested for it. Unless a lawyer puts it in front of a judge it just isn't thought of. The authorities seem to have a very convenient ignorance-is-bliss policy towards combat-related PTSD in the prison system because, hey, if there's no official way to diagnose it then 'who cares'?

My discovery led to the realisation that many other ex-soldiers in the prison population might have PTSD but have never been checked for it.

The Government are paying around £340 million of taxpayers' money per

year to keep 8,500 former troops/veterans in the prison population without even treating them for combat-related PTSD. It's better and cheaper [for them] to keep quiet.

All inmates in the prison system have to complete a Prison Services' Rehabilitation Programme which is focused on 'Offending Behaviour' courses, which are (supposedly) designed to lower the risk of prisoners reoffending. However, if you are a veteran unknowingly suffering combat-related PTSD you will, like me, pass through all these offending behaviour courses without knowing about PTSD and the reason why you came into prison in the first place.

I started to campaign while in prison for PTSD to be something that should be looked at whenever veterans are on trial because I'm angry that it was completely ignored for me. It has been confirmed now that my PTSD played a part in the crimes I committed so I feel like the outcome could have been very different.

- Jimmy Johnson was talking to Cathy Reay
- Veterans in Prison has published a survival guide for combat-related PTSD in prison, which can be viewed at [www.vetsinprison.org.uk](http://www.vetsinprison.org.uk)

# Cerrie's sense of herself

Children's TV presenter Cerrie Burnell tells our style guide **Lara Masters** about her ambitions beyond where she is now and how her own sense of self will help her get there



**C**errie Burnell is well-known as the CBeebies presenter who found herself at the centre of a furore for unashamedly showing her handless arm rather than wearing a clumsy and impractical prosthesis or covering up the limb to protect the delicate sensibilities of a few parents. Cerrie approaches her sense of style in the same way; comfort is key and she feels little need for artifice.

"My style is relaxed," Cerrie explains. "I can be glamorous when I go out but it's laid-back glamour; I'll add a gold belt to a charity shop find or wear knee-high boots and tight jeans with a little black dress over the top. My look is very seasonal; in summer I'm in sandals, brightly coloured skirts and sarongs and in winter I'll wear lots of black, higher heels and big woolly scarves, berets and boots; my Uggs are never far from me."

"I've never really worn make-up; I find it tiresome and I don't buy into this celebrity culture and women having to look and dress a certain way. I'm always pleasantly surprised to see someone in the public eye going around without make-up because a normal woman doesn't have the time to put that much energy into her appearance. Of course I want to look attractive but I don't think that means having half a pancake on your face or being trussed up like a turkey in a corset. I think we worry far too much about body image in this country."

As I think "Ugg" boots are the ugliest footwear ever invented, I have a sizeable make-up collection and a closet full of corsets which I think make a woman look sexy not "fowl" (and great for back support), it's safe to say Cerrie and I are stylistically polarised. However, I agree our society's preoccupation with physical appearance is disproportionate as was demonstrated when Cerrie



MARK MAINZ/SUNDAY HERALD

received comments from parents that her appearance on TV "frightened" their children.

"At the time of the complaints my daughter was 4 months, so I didn't have

### My disability is part of who I am, I don't know how it affects my life because I don't know what it's like not to have it

much time to worry about it but I never felt it was about me personally but about disability. There have been a few disabled presenters and many disabled characters on TV but there has never been this outcry before and I felt lucky to be able to put my viewpoint across. Parents came out in support of me and the situation saying they didn't want their child to grow up thinking that you should hide a disability or difference.

"I haven't worn a prosthetic arm since I was nine. I always push my sleeve up so I can use my arm, it would be totally impractical to cover it up."

My disability is part of who I am, I don't know how it affects my life because I don't know what it's like not to have it. I do know my back's screwed from pushing a pram and dragging it upstairs with one hand. And people recognise me even though I look completely different off-camera because they see my arm. A lot of the time it's delightful – meeting and talking to children – but there are times, like when I'm with my daughter in the park, when I don't want to be entertaining other people's kids."

Of course disability also impacts career choices. Cerrie wants to pursue an acting career and admires Kate Winslet's work and the quirky roles she chooses. I suggest that the entertainment industry is image-obsessed and Cerrie may have to focus more on her looks to succeed but she disagrees.

"I don't think you have to put more of an effort into appearance in this industry. If you're going for a casting you have to research the character and dress in a way that's appropriate for that role."

As Cerrie enjoys a successful career in children's TV, her style of understated glamour works well. However, I believe when working in the visual mediums generally, especially film, it helps to enhance your appearance in any way you can – particularly when you have a disability and are fighting deeply embedded prejudice.

My style suggestion for Cerrie would simply be to introduce make-up. Even a touch of eyeliner and mascara would make a *Titanic* impact when schmoozing directors and soon she may have more in common with Ms Winslet's career than just *Little Children*. Being the first one-handed actress on the big screen, Cerrie really would be carving a *Revolutionary Road*. I'm stopping now. ■

# Tales from Tallinn

## Old meets new in Estonia

A few months ago **Ivy Broadhead** set off to Helsinki on a year-long University Exchange. While there she's determined to see as much of and as many surrounding countries as possible. First stop Tallinn, the capital of Estonia which lies just across the Gulf of Finland. You can easily do it in a day, but she decided to book a hostel and stay overnight to really get a taste of the city

**P**eople have lived in Tallinn for around 5,000 years, but getting off the ferry I had the strange sensation of having arrived at some kind of medieval Disneyland, with costumed waiters and waitresses beckoning from every restaurant, and ye olde Estonian food, drink and souvenirs to buy on every street corner. You can eat hearty old-fashioned fare from wooden plates, served by smiley young women in bonnets and shawls. When we stopped for lunch at a restaurant which was also a microbrewery, our flagons of beer were brought to us by men in knee breeches. It was a strange experience. The food was as I'd expected, simple and heavy on the meat and potatoes, but good nonetheless.

We saw the main sites in a couple of hours – starting with the ornate

Alexander Nevsky Russian Orthodox cathedral, where we accidentally interrupted a Sunday service. This was an experience in itself for someone used to the more basic Church of England deal; all mysterious chanting and flickering candles, with head-scarfed women crossing themselves in front of ornate altars. Like Finland, Estonia was once part of the Grand Duchy of Russia, and from some of the architecture the link is clear to see. There is also the plainer Lutheran Toomikirk, and the Estonian Parliament Building, which was once the Royal Palace, as well as the old city walls, now home to various stallholders. The old, walled part of the town is small enough to be able to set off on an aimless wander and find yourself back at your hotel half an hour later, but it's a lovely city



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**The newer part of the city seemed to be okay on access, although some might struggle in some parts of the old town - cobbles were a prominent feature, so expect bone-juddering if you do use a wheelchair**

to walk around or sit and enjoy some café culture and watch the world go by. Busy and hectic it isn't, but it has an old-world, sleepy charm that certainly makes it worth a visit, although a day or two might be enough.



Locals claim that Santa Claus lives in Estonia and Tallinn's Old Town hosts a traditional Christmas market from the end of November to the beginning of January every year, when you can try traditional Estonian holiday fare, and meet Mr Claus himself. The month before, Tallinn is taken over by the International New Music Festival for five days or so in October, which throws a spotlight on choirs, orchestras, dance theatre and the rest, with work by new and well-known musicians, composers and choreographers.

As a small country with plenty of coastline to attack, Estonia has a history of being invaded and occupied. They've all been there, from the Danes to the

Russians to the Swedes, and of course the forces of the Third Reich during World War II. In the parcelling out of territory which followed Germany's defeat, Estonia became part of the Soviet Union from whom it gained independence in 1991. It is already much more prosperous (and so less cheap) than other Eastern Bloc countries. The recession has hit Estonia hard, but when we visited the tourist industry still seemed to be going strong.

### Did you know?

Estonia has about 1,500 islands and islets – not bad for a country that's only about 45,000km

We stayed at the Old Town Alur Hostel which was cheap and basic; we paid the equivalent of about £10 for a room with twelve people sharing, about five minutes away from the main square, Raekoja Plats in the lower part of the old town. The hostel itself wasn't wheelchair accessible, but the Estonian tourist board website assures me that there is more accessible accommodation on offer.

The newer part of the city seemed to be okay on access, although some might struggle in some parts of the old town – cobbles were a prominent feature, so expect bone-juddering if you do use a wheelchair. There are buses and trams, and tickets can be



bought in kiosks or from the driver, although the city centre is certainly small enough to cover by foot.

The Estonian language is notoriously difficult; along with Finnish and Hungarian it is part of the Finno-Ugric group of languages, which are pretty much alien to any European language you can think of. Luckily, everyone speaks perfect English, and you can get by in all shops and restaurants without even opening a phrasebook let alone attempting to master the pronunciation. And again, although Estonia does have its own currency, the Estonian Kroon, you can use Euro in many of the main shops and restaurants, as well as on the ferry over (also a great way to use up leftover Kroon).

Just as Brits flock to Prague or Budapest for a cheap, boozy weekend, Finns head to Tallinn. It's only a couple of hours away by ferry, quicker if you don't mind paying a little more, and the limit for how much you can bring across the border seems to be however much you can possibly lift, drag or wheel onto the ferry. So quite a lot then. On the



Old street in Tallinn

### Did you know?

Tallinn is twinned with Dartford

ferry back we queued up behind sweet-looking old ladies wheeling trolleys laden with Lonkkero (a kind of gin/mixer thing, very sweet, very Finnish), beer or the hard stuff. We caught the 8.55 ferry, and were impressed to see the Finns getting stuck into the booze already, and indulging in some good old Finnish tango on the dancefloor (not quite as fiery as the

Argentinian version, predictably enough, but they do love their tango).

I have to admit that after weeks of complaining about extortionate Finnish prices I did rather take advantage of how cheap drinking is in Estonia, ignoring the tut-tuts of disapproving Estonian cashiers and security guards who have had quite enough of Finnish tourists turning up, getting drunk, making a mess of the place and jumping on the ferry home.

Tallinn isn't all about drinking though, there's also good wholesome food to be eaten, beautiful churches to



Tallinn Town Hall

IVY BROADHEAD

**After weeks of complaining about extortionate Finnish prices I did rather take advantage of how cheap drinking is in Estonia, ignoring the tut-tuts of disapproving Estonian cashiers and security guards**

look at, and traditional touristy crafty things to buy. The contrast between the old and new parts of the city is striking; towering skyscrapers a stone's throw from quaint cobbled streets and churches and old city walls.

The city is home to about four hundred thousand people, but these are mostly concentrated in the newer part, which from what we saw was mostly shops, offices and tower blocks, and the old part of the city feels pretty small. We had hoped the cheap Estonian prices would extend beyond food and alcohol to clothes and other desirables, but from what we saw it was pretty similar to Finland, so a good £10-20 more expensive than the equivalent in the UK. If you're after some cosy Estonian-knitted socks, fetching woolly jumpers or a hat made of bits of dead animal then go for it, but for more standard stuff I'd leave the shopping for when you get back home.

If you think Tallinn doesn't warrant a trip for its own sake, good fast ferry links mean you can easily tie it in with a



IVY BROADHEAD

### **The Alexander Nevsky Cathedral**

trip to Helsinki or Aland in Finland, Stockholm in Sweden or even Rostock in Germany. Of course there is more to see beyond just the capital city, and on the return ferry a French guy I'd met told me about his visit to the Klooga concentration camp to the north of Estonia, where up to 3,000 inmates at a time were held during the Nazi

occupation, many of whom died at the camp. The stuff of a light weekend mini-break it might not be, but if you get the chance I'm sure it could be a moving and important experience.

Estonia is famous for its health spas, with over a dozen in the capital alone, offering treats like hot stone massages and chocolate body wraps.

There is also Pärnu, which is a little beach town on the southwest coast, where they have mud baths they claim can cure anything from joint disorders to dysfunctions of the nervous system, kind of like Lourdes I guess, but less clean. I can't testify as to the truth of these claims, but if that's what you look for in a holiday then good luck to you. For now I'll stick to Tallinn, and maybe leave being "cured" of dwarfism for my next summer holiday. ■

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## Windows exploring



Our technology wiz **Leonie Watson** took yet another step into the unknown on her continuing journey to seek out new computer solutions.

This one followed the launch by Microsoft of their new Windows 7 operating system. Would she boldly go where everyone else was heading

**W**indows 7 has plenty of accessibility features, aimed at helping people with a range of disabilities. These include screen magnification, an on-screen keyboard with predictive text, and the ability to use a touch screen interface. In some cases these are simple versions of existing access technologies. In others they are robust solutions in their own right.

As someone who is blind, I was naturally interested in Narrator, Windows' screen reader programme. I also spend a lot of time at my computer, so I was curious about the speech recognition as well. With scant regard for life and limb, I decided to write this article using only these two access technologies. Let the adventures begin!

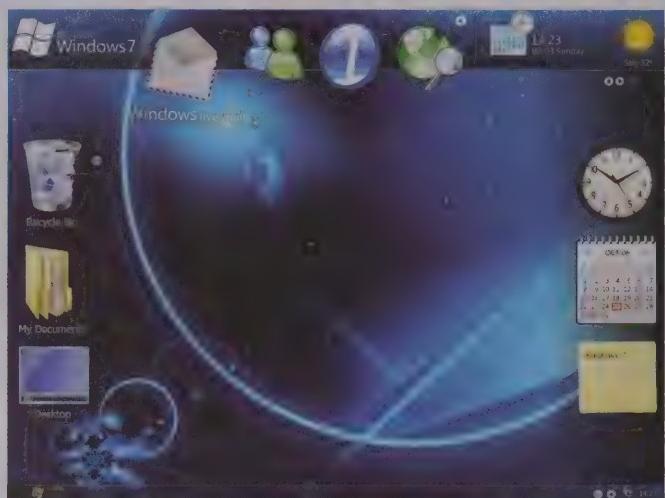
The first thing I noticed about Narrator was the quality of the default voice. With a little tweak

**I couldn't get Narrator to read any text that I'd typed into the document. Accessing menus and toolbars was no problem, but otherwise it was the end of my first adventure**

of the settings, it was reasonable to listen to. You can change the speed, pitch and volume of the voice, to find levels that suit you best.

Narrator did seem slow to respond, particularly in comparison with the established screen readers. Once you tune into the slower pace though, the level of information available is remarkably good. With only minor bumps and bruises along the way, I was soon exploring the desktop, opening programmes, using Notepad and reading my email.

Full of confidence, I opened Microsoft Word and settled down to write this



article. I was foiled at the outset though. I couldn't get Narrator to read any text that I'd typed into the document. Accessing menus and toolbars was no problem, but otherwise it was the end of my first adventure.

Undaunted, I reverted to my usual screen reader, plugged in my microphone and started up the speech recognition programme. We intrepid explorers don't usually worry about tutorials, but with speech recognition it's important to train Windows to understand your voice. It's a very easy process though.

Within moments, commands such as "Next", "Open", and "Undo" were ringing out. Not waiting for a moment, I opened up MS Word with a simple voice command, and began dictating this article.

The accuracy of the recognition was surprisingly good. Even without using my best

BBC voice, I was able to dictate this article with only a few mistakes. Happily chatting away, I'd conquered yet another frontier.

So what of future voyages in cyberspace? For me, Narrator will be a handy, if limited alternative when my main screen reader stops working. For others, it may provide a free solution. In terms of speech recognition, I've already bought a headset microphone for better quality. It will be a useful way of writing long documents and pretending I'm on Star Trek. For others, it may be a viable solution to accessing a computer without a mouse or keyboard.

### INFORMATION

Windows 7 is available in several versions direct from Microsoft and other well-known software dealers. Prices start at around £80.



# Fuelling forecourt frustration



Disabled motorists are getting fired up and chippy, says **Helen Smith**, over problems at the petrol pump



**T**he story of Berkshire motorist Linda Guttridge finding it difficult to get served at a petrol station and subsequently having problems paying is sadly not uncommon. For many disabled drivers getting fuel is not a pleasant experience and it is one which I personally try to avoid as much as possible by getting someone else to

do it for me. However, that's not always possible and so I know only too well how Linda feels when faced with the prospect of trying to get fuel.

The problems usually start on arrival at the station where the first job is to get the attention of the attendant inside. This can be a simple job if the attendant recognises the buzz from service-call

([www.service-call.net](http://www.service-call.net)) but more often than not they don't know what it is. On one occasion after waiting for at least 15 minutes I gave up pressing the service-call and hooted my horn instead. Eventually when the attendant finally came out they told me they thought service-call was their freezer making a funny noise. Service-call is a great invention but staff need to be informed what it is and what it sounds like.

There is also the problem of going to a petrol station where there is only one person on duty. The likelihood of them locking up the shop to come out to help you is next to none. When faced by this problem I've had to ask a stranger to help fill my car up with fuel. The next problem this then brings is having to pass your credit card over to them to pay for you in the shop. I haven't done this since the introduction of chip and PIN as fortunately, having acquired some better artificial legs, I am

now able to get into the shop and pay myself, but if I couldn't I don't think I'd have been at all happy handing my PIN number and card over to a stranger. However, this was exactly what Linda Guttridge was doing. She had been giving her PIN number out to staff as she was unable to get into the shop and they couldn't bring the PIN terminal onto the forecourt.

When chip and PIN was first introduced the disabled motorists' organisation Mobilise raised the problem disabled drivers would face

**— There is also the problem of going to a petrol station where there is only one person on duty. The likelihood of them locking up the shop to come out to help you is next to none —**

and were told by the banking industry that anyone who finds it difficult to use chip and PIN cards is entitled to apply for a chip and signature card instead. The way a chip and signature card works is when it is put in the reader it generates a slip for a signature. However, not all banks have been willing to give these cards out. In a

recent piece of research carried out by Mobilise it was found that disabled people were still experiencing problems getting hold of chip and signature cards.

Although in the past, health and safety regulations have prevented electronic devices such as chip and PIN terminals from being used on the forecourt, regulations have been amended to allow for the use of portable card terminals suitable for petrol station forecourts. However, few if any have introduced them. Sandra Quinn,



Director of Corporate Communications for The UK Cards Association, said: "Whilst we urge petrol station retailers to upgrade their technology, the reality is, until mobile chip and PIN terminals are widely

available, many disabled drivers may not be able to have a terminal brought to their car."

In addition to these problems some stations are doing away with attendants completely, meaning getting

served as a disabled driver is next to impossible, and in my opinion are to be avoided if at all possible. However, some disabled people prefer the automated pumps as it does away with struggling across the forecourt.

Although getting fuel can be a pain many disabled people have improved the problem for themselves by buying service-call, going to the same petrol station where you are recognised or where you know there are several staff members, and getting a chip and signature card.

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## Malone in a class of his own

Detractors of Paralympic sport say the one thing that stops it being like "real" sport is the arcane and arbitrary classification system for many of the athletes. **Paul Carter** reports on one athlete's battle to be recognised for what he is



PARALYMPIC COUNCIL OF IRELAND

**Home Malone:** Derek Malone following his expulsion from the 2008 Paralympics in Beijing

It was one of the major controversies that threatened to overshadow last year's Paralympic Games. The classification of disabled athletes has always been one of the International Paralympic Committee's most important issues, forming the cornerstone of

competition allowing people with wide-ranging impairments to compete equally.

However, at the 2008 games in Beijing, that classification process turned out to be so rigorous, that it resulted in several athletes being reclassified on arrival, while others were sent

home altogether, some just days before they were due to begin competing.

Derek Malone, a member of the Ireland cerebral palsy football squad, was one such victim of the process. Malone was adjudged to be "not disabled enough to compete" by the sports governing body, the

Cerebral Palsy International Sport & Recreation Association (CPISRA), and was dismissed from the Paralympic Games, and has since missed out on the International Championships in Holland.

Malone always contested that the fact he was deemed to have too much movement was merely due to hard work and physical conditioning.

Following a lengthy 13-month campaign against the decision by Malone, the Paralympic Council of Ireland (PCI) and Cerebral Palsy Sport Ireland (CPSI), the decision has been overturned, reinstating him to compete.

Malone, who called the last 13 months "the worst of my Paralympic career", said the decision was bittersweet.

"I have mixed emotions at this moment," he said.

"At the end of 13 months I am delighted I have won my battle to get the decision of ineligibility made by CPISRA at Beijing 2008 overturned. I've been reinstated permanently as a CP 8 with immediate effect, a decision which is incontestable."

"My delight is tempered by the fact that CPISRA are unwilling to apologise to me and the Irish team for the proven flawed decision, that ruled me out of the

Beijing Games and the subsequent International Championships which are currently underway in Holland.

"I hope that CPISRA can still look within their organisation and find the honesty and sense of decency to admit that I was wronged in Beijing. This will allow me to draw a complete line under the events of Beijing 2008 and move on."

Secretary General of the Paralympic Council of Ireland, Liam Harbison, was equally angry about the

handling of the decision. He said: "I am thrilled that the wrong perpetrated on Derek Malone, and the Irish team as a whole, at the Beijing Paralympic Games by CPISRA has been corrected.

"Having said that, while recognising the process that brought about this week's reinstatement, this decision should have been made much sooner which would have permitted Derek Malone to compete at the International Championships this week."

Harbison continued, "I welcome the fact that CPISRA have reviewed their rules and procedures in light of the terrible distress caused in Beijing by Derek's case, but I do feel they still haven't addressed one of our core concerns, namely, that the symptoms of cerebral palsy as a condition are trainable and can be developed to a significant degree by elite athletes.

"I hope that CPISRA will continue to review their classification rules, and be more consultative with the athletes and playing

nations in doing so."

Irish Football seven-a-side team manager, Paul Cassin stated: "In my 30 years of involvement with CPISRA, both myself and my players have always treated classification with honesty and endeavour.

"I am delighted with the help of the Paralympic Council of Ireland that we finally have closure on this matter.

"I very much look forward to welcoming Derek Malone back into the Irish Panel and seeing him in the Irish jersey once again."

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# entertainmentnow

# Kinshasa heat

From busking in their home city to a genre-defining funk album and sold out UK tour, Staff Benda Bilili are taking their unique Congolese sound around the world. **Cathy Reay** went to meet and see them in action



© BELLE KINNOE

From left to right: Djunana, Roger, Théo, Randy, Ricky, Coco

In the Congo we play on the streets in front of restaurants, or wherever we know that there are people who might pay us something."

Leon "Ricky" Likabu is

about to get the shock of his life. He's speaking to us just hours before he is set to join the rest of his band of paraplegic melody makers on a stage in front of 1,500 plus people at London's

Barbican Centre, who have individually paid more to see them than they might make in a day on the streets of their home town, Kinshasa. This is the beginning of the biggest tale of rags-to-

riches you are going to hear this year. And the greatest thing? Nobody believed they could do it.

"Of course we have other jobs!" he tells me almost incredulously, as if the

suggestion of being a full-time musician is entirely implausible. Thing is, until now it kind of was. In Kinshasa, capital of the Democratic Republic of the Congo, life is simple. There is little electricity and precious little connection to the outside world. And of course this means that inside that world, anything that might be a bit different from the norm is treated with a mixture of disbelief and caution. So when Ricky, Coco, Théo et al tried to join 'regular' bands, they were turned down, laughed at: "you'll be late for everything, you'll hold us up, they'd say. So we came together and made our own band."

And what a band they are. Ricky, who plays guitar and shares vocals with Coco Ngambali, Théo Nsituvuidi and Djunana Tanga-Suele, all of whom are in wheelchairs are joined by Kabamba Kabose Kasungo on crutches, Cubain Kabeya on percussion and drums and 17-year-old prodigy



© VINCENT KENIS

### Ricky and Coco

Roger Landu on the satonge, a single-string instrument of his own invention that produces a sound more wild and high-pitched than any kind of guitar we've ever heard.

Though I'm told this is roughly the 'permanent' line-up, the faces change almost daily according to who can make each performance, whoever can be bothered to show up.

When they do hit the stage the following evening, in front of a predominantly white, non-disabled, middle-class crowd, Staff Benda Bilili, who don't speak a word of

English, have nothing else to give other than a breathtaking two hour frenzied performance of mind-blowing funk and rumba. The wheelchairs don't stop the 50-something musicians, in cowboy hats and cheap tailored suits, from grooving in their seats and Djunana goes so far as to leap out of his chair, sprawling across the floor in hypnotising discombobulated dance moves. By the end, the whole audience is up from their seats imitating him, not in pity, but because he

looks like he's having such a good time.

"Our message is that if your head is 'working', anything is possible. We shouldn't wait for others to take care of us; if you fight for yourself, you can achieve," says Ricky.

And it seems like Staff Benda Bilili are doing just that. In a native situation where disabled people have to beg just to get by, these men are going above and beyond to try and ensure that 'just getting by' is not the motto of future generations of the Congolese 'handicapped', as they call themselves.

"It took a long time, but now we're finally recognised as good musicians in our own country," Ricky smiles. He says his band wants to be the best musicians in Africa and, while this might be a steep dream, they've definitely come a long way from the streets.

- **Staff Benda Bilili's** debut album *Très Très Fort* is out now through Crammed Discs [med.be/staffbendabilili/](http://med.be/staffbendabilili/)



© BELLE KINOISE

# webwatch

## Days of Future Past

Recently voted one of the top ten fourth plinth exhibits in Trafalgar Square, performance artist **Liz Crow** finds solace from the past in the past present and future

**Roaring girl PRODUCTIONS**

- Productions
- Projects
- Training
- Publications
- Personnel
- Legal
- Links
- Contact

6 November 2005

**Open Road**

Directed by [Liz Crow](#)  
Produced by [Sue Fairbanks](#)  
2005 10 x 5-second bites  
Shot on mini-DV

[d]

Think *Priscilla Queen of the Desert*, *Top Gear*, and a little hippy chic, as a red van drives through the West Country countryside. *Joie de vivre*.

*Open Road* was made for CobraVision and screened on

**M**y computer days began with the heady technology of the early 1980s, when my soul was saved by the Microwriter.

Thanks to Roger Jefcoate at the Foundation for Communication for the Disabled (now Abilitynet at [www.abilitynet.co.uk](http://www.abilitynet.co.uk)), this little hand-held device meant I could commit my words to paper for the first time in a decade. Granted it held a maximum of three pages and most of my time at university was

spent running back and forth to printers, emptying the computer ready for the next lecture, but this was true liberation.

Eventually I discarded my Microwriter in favour of newer technology and I've regretted it ever since. I found a picture on the web recently ([www.old-computers.com](http://www.old-computers.com)) and was suffused with fondness.

My next big venture into the technological frontier was in the late 1990s on a visit to California when I discovered the internet (though not all by myself).

I searched on "disability" and the world wide web delivered a full four sites. A Google search today has netted over 47 million links in 0.47 seconds.

Email didn't convince me at first, not least because no one I knew had signed up yet, which made it a bit like talking to myself. But Helen Keller changed all that. In 1999, I made my first film (*The Real Helen Keller*, co-produced with Ann Pugh), filming on the other side of the Atlantic. Email solved the time difference, saved the project a fortune and had me hooked.

My own website ([www.roaring-girl.com](http://www.roaring-girl.com)) followed soon after and is key to getting my work to an audience. My current project is *Resistance*, a moving image installation that takes as its starting point the Nazi campaign against disabled people and its contemporary echoes.

As we prepare to launch at Liverpool's DaDaFest on 17 November, we're reauthoring the site to make it more interactive and I'm turning to the web even more to grapple with

social networking and twittering. When it all gets too much, I turn to the Slap Nick Griffin website ([slapnickgriffin.co.uk](http://slapnickgriffin.co.uk)) and that makes me feel a little better. (After attracting 20 million slaps, the site has now been taken down.)

There's a fine balance with the web – that point where the freedom of the highway turns into a sticky fly trap. For relaxation, I tend to move away from the screen. But I do like the Longplayer (<http://longplayer.org>), a 1000-year musical composition that's the antithesis of instant internet gratification and I like to browse Woodlands ([woodlands.co.uk](http://woodlands.co.uk)) dreaming of a little patch of green where I can pitch my tent...

Recently, when life seemed to operate only through a keyboard, I reminded myself of that early Microwriter liberation. I'd like a little time away from technology, but I know I'll be back.

Meantime, if anyone's got a spare Microwriter taking up space in the back of a cupboard, let me know.

### → Have your say

- write to us Disability Now, 6 Market Road, London N7 9PW
- email us [editor@disabilitynow.org.uk](mailto:editor@disabilitynow.org.uk)
- phone us 020 7619 7323

# worklife

## Fast track to Whitehall

**Arabella Scott** is a graduate who recently undertook an internship as part of the Fast Stream Summer Placement Scheme, managed by the Cabinet Office and Scope. She talks about experiencing life inside the Civil Service



I did a two-month internship at the Ministry of Defence (MOD) this summer, as part of a scheme for disabled people, to give them experience of working in government and to encourage them to apply for the Fast Stream, which is a graduate recruitment programme for the Civil Service.

I was working in procurement. It was a very interesting time to be there, as obviously the MOD was in the public eye quite a lot, so to actually see things behind the scenes and to see the difficulties and challenges of the way a government works rather than just from the outside – I loved it,

**Ultimately I'd love to end up in the Middle East working either in the Foreign Office or being seconded by one of the other departments**

absolutely loved it.

We were given choice in the sorts of areas that we wanted to work in, areas of interest, and they tried to put us there as much as possible. I'm interested in foreign policy and strategic areas so either the Foreign Office or the Ministry Of Defence would have been useful, so it was really good

to be able to be placed where I was really genuinely interested.

I found it massively worthwhile. It was so positive. I haven't always been disabled (I have a spinal injury) and with just getting to the end of being a student, along with beginning to think what the job market's like, and trying to get a job as a disabled person and was there any discrimination, I was so pleasantly surprised how hard they worked towards making every effort to make sure I could work effectively and well. There was absolutely no stigma at all. They train up all the staff in awareness and I really felt that they were very advanced and I felt really welcomed.

I graduated with a degree in politics from Durham University last summer and I'm doing a masters there at the moment in International Relations.

I'm now applying for the Fast Stream, so I'll see how far I get.

There are online tests, additional assessments and there's also an all day test. Obviously they also look at

your CV beforehand, although the assessment centre day is the main way that they test you and see that you've got the competency that they're looking for.

It's hard to think about long-term plans when you haven't experienced it, but the Fast Stream is a five year programme where you get to experience five different jobs in five years. So they give you loads of different experience so you can see which areas you're interested in, whether it's policy or strategy etc.

I think ultimately I'd love to end up in the Middle East working there either in the Foreign Office or being seconded by one of the other departments.

- Arabella Scott was talking to Paul Carter

### ARABELLA SCOTT: CAREER PATH

- 2008 – Durham University – Politics degree
- Summer 2009 – Fast Stream Summer Placement Scheme
- 2009 – Present – Durham University – International Relations masters degree

**FOR SALE** - Tel: 020 7619 7336, Fax: 020 7619 7331,  
Minicom: 020 7619 7332, email: patrick.durhammatthews@disabilitynow.org.uk

## CARS/VANS/CARAVANS

### CITROEN BERLINGO

**MULTISPACE** Forte 2.0 Hdi, Sahara Gold, 2003 (53 plate), air con, e/windows, 109k miles. Wheelchair Conversion by Brotherwood incl lightweight manual rear ramp with electric winch. Carries max of 5 including wheelchair. One owner from new, full recent MOT and fsh. In very good condition, reliable and economical. £4,450 ono. Tel: 01453 825298 (Glos) or mobile: 07931 506079.

**FORD FOCUS 1.6** Zetec 3 door automatic hatchback, silver, 2002 (02 plate), alloy wheels, body coloured bumpers, driver's airbag, front e/windows, CD player. With Constables Wheelchair Conversion incl free electric wheelchair for front passenger with electric lift. Original passenger seat and door card available if required. Only 17k miles, full MOT, 2 owners from new with full fsh. In very good condition, £4,950 ono. Tel: 01424 844722 (Bexhill-on-Sea, E. Sussex) or mobile: 07946 489849.

**VOLKSWAGON SHARAN GLX** auto, central locking, e/windows and mirrors, sun roof, air conditioning P reg (1996) 82,000 miles Metallic Green. Gowrings Wheelchair Conversion with manual ramp at rear with inertia belts and securing system. Carries 4/5 including wheelchair, centre rear middle seat can be taken out to provide more space. MOT 'til October 2010 (12 months) and taxed for 6 months. This vehicle is a sound runner but has cosmetic damage to some panels of the bodywork and front bumper, hence asking £1,250 ono. Tel: 01939 200567 (Shrewsbury, Shropshire) or email: carl.ford@btconnect.com

### MERCEDES V220 CDI

Ambiente, auto 6-seater estate car. Silver, 2000 cc, diesel, 22k miles, 2002 plate. Top spec, vgc, one owner from new, fsh, full MOT, adapted by KC Mobility Services. Pas, central locking, air con, twin electric sunroofs, front and rear electric windows and privacy glass, heated front seats and mirrors, radio with mini-disc player, integral Smartnav from Trafficmaster. Automatic side door with electric hoist, electric hoist at rear door, electric and manual hand controls, Parkatronic with reversing camera. Turney front passenger seat and electric controls for driver's seat allowing the car to be driven by the disabled user and access to front seat is possible both by someone on crutches or from a wheelchair. The original layout of the car is to have 4 upholstered seats and one table in the rear. To facilitate the positioning of the wheelchair and electric scooter, the table and 2 chairs are in storage but available if wanted. Total cost £33,716, asking £16,000 ono. Tel/fax: 0161 976 4436 or email: drleslie@onetel.com

### VOLKSWAGEN TRANSPORTER

**1.9**, Tdi, SWB, medium roof, metallic silver, pas, central locking, air con, CD player, ABS brakes, all round windows with privacy glass and centre sliders. Lewis Reed Wheelchair Conversion incl rear access via ramp with winch. 2 wheelchair positions, one behind the other with inertia belts for stability. Carries a maximum of 6 people with 2 wheelchair or 7 people with one. Only 11k miles, bought November 08, 2 year engine, paint and roadside assistance warranty, 12 year anti-corrosion warranty. In immaculate condition, £21,000 ono. Tel: 01564 826429 (Solihull) or email: harkinconst@aol.com

### RENAULT KANGOO 1.4

central locking, CD player, dark blue, registered Feb '02. With Gowrings Wheelchair Conversion incl lowered floor with rear ramp which is easily lowered. Carries 5 including wheelchair. Serviced every year, only 39k miles, MOT expires March end. In very good condition, asking £2,800 ono. Tel: 01935 473299 (Yeovil, Somerset).

## WHEELCHAIRS/SCOOTERS

### MINI CROSSER M1

model (Medema Group), 4-wheel all terrain electric scooter with plastic garage, variable speed settings with a maximum of 15 mph, 40 miles on full charge, registered for road use, silver, with headlights, rear lights and brake lights. With hooter, basket and full sized bag at rear. Adjustable seat and steering controls. Never been used, bought only 2 weeks ago, with full instruction manual and guarantee on everything for 3 years. Bought for £4,650, asking £3,500 for quick sell. Tel: 01787 273553 (Halstead, Essex) or email: maurice.fleming3@btinternet.com

### PRIDE QUANTUM 610

electric wheelchair, max speed 8 mph and max range 12 miles. Navy blue, with kerb climber, hooter on control panel, with footplate and spare pair of adjustable side swinging footplates. With full instruction manual, used for less than a year, reliable and in good condition, asking £1,500 ono. Willing to display locally. Tel: 01989 768085 (Ross-on-Wye) or email: nicolabrandt@hotmail.com

### IBOT 4000 STAIR

climbing wheelchair. Climbs 5" stairs, 4 wheel drive, all terrain spec (mud and sand), max speed 6.8 mph, 20 miles on full charge, wheelchair rises to eye level. 3 years old, cost £22,000, in good condition, bargain £10,000. Tel: 07968 571104 (Eastbourne) or email: disawareuk@hotmail.com

## HOUSEHOLD & FAMILIES

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## SOS

**A KIWI HEADING** to the UK for Christmas is in need of an insulated accessible caravan. The caravan must have a wet area shower and a toilet as well as 2 beds (for both myself and carer). The caravan requires a ramp or a hoist, as I cannot lift my feet very high at all. The caravan would be parked up at my brother's place in Woking in Surrey, and used on the roads other than delivery etc. As we are not sure of our itinerary as I love all 4 countries of the UK, but I guess we may head up to the highlands of Scotland, up Inverness way at some stage, so any assistance with accommodation, of any sort, in any area, as long as there is a wet area shower, (would only

Cont'd pg 63

**RECRUITMENT**

## Disability Careers opportunities at Tower Hamlets

Here in Tower Hamlets, valuing diversity is one of our four core values. It's all part of our desire to build One Tower Hamlets – a borough where everyone has an equal stake and status. Members of the disabled community are not only welcome to join us, but will benefit from recognised support, including a Staff Forum and a whole range of borough-based support groups. To find out more about the careers on offer and our commitment to diversity, visit

[www.towerhamlets.gov.uk/disability](http://www.towerhamlets.gov.uk/disability)

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need this every second night), toilet and very few steps. Into the future a wee bit, when I finish work in a year to 18 months, I would be very interested in a) a house/car swap, which would be in Dunedin in the South Island of New Zealand or b) for a person I can stay with, who could show me around their country and, in return, I would show them around the South Island of New Zealand. Tel: 00 64 3454 2463 or email: [ibby@kol.co.nz](mailto:ibby@kol.co.nz)

## JCMBPS seeks new member

Do you have experience in mobility and transport issues for blind, deafblind or partially sighted people? Would you like to help us make a difference?

The Joint Committee on Mobility of Blind and Partially Sighted People (JCMBPS) is an independent body consisting of representatives of the principal national organisations of blind, deafblind and partially sighted people with a specific interest in access, mobility and transport issues.

In addition to a range of member organisations from the visual impairment sector, and observers such as the Access Association and Association of Train Operating Companies, the Committee has places for three co-opted individual members. There is currently a vacancy for a co-opted member.

The JCMBPS works with central and local government, transport providers, and others responsible for the design, development and operation of the built environment and transport systems to ensure the requirements of blind, deafblind and partially sighted people are recognized and taken into account.

Our priorities for this year are the pedestrian environment; public transport including audible announcements on buses; and mobility and technology including the implications of hybrid/electric 'quiet vehicles'. We are particularly looking for someone with useful experience in one or more of these areas.

The Committee meets four times a year, normally in central London, and travel expenses can be available. Work outside these meetings is done in Task Groups, normally by email. So – if you have experience in mobility and transport issues for blind, deafblind or partially sighted people and would like to help us make a difference please contact the JCMBPS

secretariat by 31 December 2009: Email [jcmbps@guidedogs.org.uk](mailto:jcmbps@guidedogs.org.uk) or ring Gill Kenyon on 0845 241 2178. Website: [www.jcmbps.org.uk](http://www.jcmbps.org.uk)



## RECRUITMENT



# ROYAL LONDON SOCIETY FOR THE BLIND

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*The Vision to make a difference*

*"Would you like to bring some COLOUR to visually impaired people's lives?"*

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For Charity for Blind and Partially Sighted People



The RLSB is an innovative charity that provides education, training and employment services for people who are blind or partially sighted and we have exciting plans for future developments.

Did you know that 75% of blind and partially sighted people don't achieve employment? At the Royal London Society for the Blind we believe that blind and partially sighted people should be fully included in society, on parity with their sighted peers. We are committed to working in communities across London and the South East to promote the social inclusion of children, young people and adults with little or no sight by providing education, training, support and employment services for them. Our vision is a society where visual impairment is not a barrier to personal fulfilment or social inclusion.

Could you help us achieve our mission to remove barriers to personal fulfilment and social inclusion, through our services, meeting the needs of blind and partially sighted people in contemporary society. We are currently seeking new trustees to join our Board. This is an exciting time to join us, to direct and resource the delivery of a 5-year strategic plan. We are committed to growing our income, raising our profile and developing a range of programmes.

Do you have an interest in education, training and disability rights issues? Have you some knowledge of one or more of:

- Initiatives that have promoted the social inclusion of marginalised groups
- Fundraising – networking and resource mobilisation
- Media – public relations and lobbying
- Financial management and Administration

Availability to attend quarterly meetings, knowledge of the voluntary sector and an understanding of governance are all essential, as is an empathy with our mission and values.

Our charity values diversity and wishes to create a Board which reflects the community with whom we work. Applications are particularly sought from people with a disability, and those from Black and Ethnic Minority backgrounds. These are unpaid appointments. Applicants are most welcome to visit any of our services by arrangement prior to meeting the Appointments Committee. For an informal discussion, call Brian Cooney (Chief Executive) on 01732 592665 or alternatively request an application pack, by e-mail or letter, from Michael Brignall, Chair of Appointments Committee, at [alison.nield@rlsb.org.uk](mailto:alison.nield@rlsb.org.uk) or c/o CEO's Office, Royal London Society for the Blind, Dorton House, Seal, Sevenoaks, Kent TN15 0EB. A comprehensive induction programme will be provided for all new trustees who join the Board.

The Society is committed to safeguarding and promoting the welfare of children & young people and expects all staff and volunteers to share this commitment.

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## 3 x 'Employment Preparation' **APPRENTICESHIPS**

(focussing on work experience Placements, Access, and Support)

Hertfordshire PASS is seeking to appoint 3 apprentices aged 18-25 years to help run WorkABILITY, a user-driven employment preparation project run for and by disabled young people.

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For more information email: [pass@hertspass.com](mailto:pass@hertspass.com) or write to  
Hertfordshire PASS; Unit 2 Brownfields; Welwyn Garden City; AL7 1AN

Deadlines for applications: 11th December.  
Selection day: 17th December

Hertfordshire PASS: 'a user-driven charity using employment to enable disabled people to live more independently' is a registered charity no: 1081277



**LOTTERY FUNDED**

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## WARNING

We have been warned about a scam involving people from overseas who say they want to buy a product and who offer to pay using cheques, Western Union money transfers and certified cheques. Although no *Disability Now* readers to our knowledge have been hit by this, please be particularly wary of accepting cheques from overseas. For more information, visit the Metropolitan Police website.

vitalise

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## DN DEADLINE

January 2010 published 22 December. Classified deadlines:  
Booking: 30 November. Copy: 2 December.

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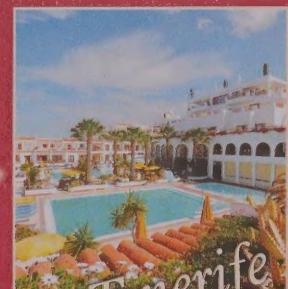
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# backlash



## Failing to crack the code

When **Paul Carter** lost his cash card, little did he know what he was about to get into. Certainly not his own bank account

**B**ankers. Oooh, there's a controversial word to start the column with. I bet you're frothing at the mouth with ire already. I am, and I can't even blame it on the drink! Actually though, my problem isn't with the gits in the striped-shirts and braces, but rather the ludicrous systems of your common or garden high street bank.

As much as I'd like to use this space to launch an anti-capitalist tirade against the downfalls of merchant banking, I fear that would be a little off brief. Maybe next time.

Anyways. I lost my bank card recently (which I can blame on the drink) and had to go through the usual rigmarole of getting the bank to send me a new card and PIN.

This isn't a new experience, I lose things all the time, but it seems that the particular organisation I bank with have adopted a new, supposedly more secure method of sending out PINs to people.

Rather than just getting a simple separate letter like I used to, I received something



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akin to a new National Lottery scratchcard, except the prize was merely the right to access my money.

You know, my money. The money that I earned that I then paid tax on that was given to them so they could stay in business and proceed to not let me access my money. That money.

This new method involved having to peel back a tiny cardboard strip attached to the letter, then scratching

off the panel underneath, before turning the letter over to try and make out the ludicrously faint letters printed on what looked like speckled knicker elastic.

Needless to say I broke it. Namely by not being able to peel back tiny cardboard strips or scratching off underwear-resembling panels.

Cue me having to visit my local branch, to sheepishly explain how I'd managed to annihilate a simple piece of

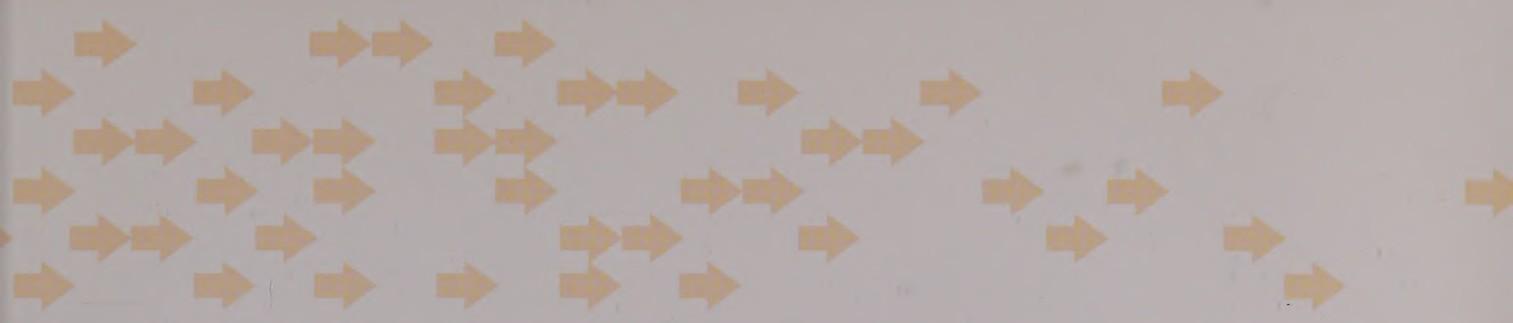
paper quite so spectacularly.

The bemused man behind the bombproof screen informed me he'd have to "order another one," which, as I explained, was about as useful as a one-legged man in an arse-kicking contest.

Bombproof man didn't look like he understood my point, although that may of course have been due to my slightly inappropriate choice of metaphor. "I'll have to order you another one," he repeated, annoyingly.

When my new PIN arrives, I'll have to find someone trustworthy to open the poxy thing for me. Given my disdain for just about everybody, this could prove tricky.

This whole scenario could, of course, just be a deliberate and ingenious ruse to recruit a slavish army (or rather a no-army) of dependent armless disabled people, forced to depend on the bank for sustenance due to their inability to access their own cash because of a deliberately inaccessible PIN system, therefore propping up a hopelessly failing capitalist system. Maybe. Check in next time to find out. Toodle-pip.



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for disabled  
people

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easy to find

**Directgov**



**www.direct.gov.uk/disability**

Directgov is the website to visit for the latest information and services from government. It's clearly written, useful and the information is all in one place.

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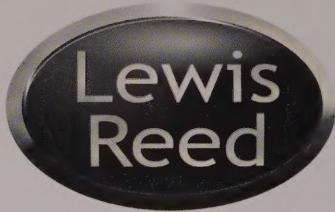
- ➡ home and housing
- ➡ financial support
- ➡ disability rights
- ➡ employment
- ➡ health and support

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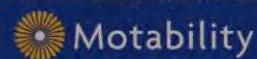
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